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ABSTRACT

This report was prepared as part of Mississippi's reporting requirements for Public Law 100-146, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. It contains the results of 300 in-person interviews determine their satisfaction with services. A descriptive analysis of the interviews is presented in six chapters covering the following topics: (1) sample characteristics (age, gender, race, marital status, primary and secondary diagnoses of handicapping conditions, and functional capabilities); (2) satisfaction with current life situations and specific programs and services (residential services, vocational services, health services, individual support, transportation services, and recreation/leisure services); (3) independence in choice of living situations, choice of occupations and leisure activities, input in medical and financial matters, and input in social matters; (4) integration into community activities, such as voting; visiting with friends and neighbors; and going to restaurants, churches, movies, and sports events; (5) productivity in jobs and other activities; and (6) level of need for support services. Findings showed a relatively high level of satisfaction for the majority of interviewees. Appendices contain the survey instrument and administrative forms. (JDD)

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ED320321

A CONSUMER SATISFACTION STUDY OF SERVICES OF INDIVIDUALS WITH DEVELOPMENT DISABILITIES IN MISSISSIPPI

THE 1990 REPORT TO CONGRESS, VOLUME II

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PREPARED IN ACCORDANCE WITH:
THE DEVELOPMENTAL DISABILITIES ACT OF 1987
BY THE
MISSISSIPPI DEVELOPMENTAL DISABILITIES
PLANNING COUNCIL

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Preface

This report on consumer satisfaction of services of individuals with developmental disabilities in Mississippi is part of the reporting requirements for each state to develop as described in P.L. 100-146, "The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987." This Developmental disabilities Assistance and Bill of Rights Act requires each state Developmental Disabilities Planning Council to carry out various planning activities, including the conduct of a survey of people with developmental disabilities themselves to discover what their experiences were and to find out what impact services had in their lives.

Mississippi, like all other states, conducted a statewide Consumer Satisfaction Survey, the results of which are contained in this Volume.

Although Congress did not require it, Developmental Disability Councils across the country decided to use the same survey instrument (Appendix A) to fulfill the mandate of P.L. 100-146, so that the responses of people with developmental disabilities who reside in all the states could be combined and compared. The National 1990 Report to Congress, therefore, will present legislators and the public with the most extensive information about the lives of consumers and their families ever collected by State Developmental Disability Councils.

The Mississippi survey consisted of 300 face-to-face interviews. The in-person interviews were focused in various parts of the state and in numerous public and private agencies as well as family homes. All know major agencies specifically serving persons with developmentally disabilities were randomly selected. Subsequently, a random sample of individuals from these agencies were interviewed. Almost all persons in the randomly selected group were interviewed.

After the interviews were conducted, the results were forwarded to Temple University where primary entry and analysis of the data were carried out for all states. Each state then received a dataset and output specific to their state.

The output that accompanied the data disk provided by Temple is a thick volume of printouts that consists largely of cross-tabulations and breakdowns of responses by the age and disability groups represented in the sample of respondents. Due to the tremendous number of possible statistics and tables that could potentially be generated from the survey data set, project staff selected important variables that were descriptive of the survey sample and touched on a range of interview items related to accessibility of and satisfaction with services. These variables were then used to generate a series of tables, charts, and graphs that formed the basis of Volume II of the 1990 Report.

We have accumulated a veritable wealth of additional data on Mississippi services and such data could serve as a valuable resource for future analysis of the Mississippi system. However, only a portion could be included in this monograph.

The research staff has serious questions about instrumentation and generally the extent to which some questions can be taken as a valid representation of the opinions of consumers toward state services in Mississippi. However, one use of the survey process would be to make a concerted effort to obtain the input of persons and groups who could provide important formative evaluation information to improve the instrument and implementation for future surveys.

As you read the following chapters, one point is important to remember: Behind the statistics, the graphs, and the tables is the reality of people's lives. Each person who responded to the Survey was telling his/her life story; combined, these stories constitute the Survey results.

Finally, the Survey process has been quite useful and has provided many valuable insights. The interviews, along with other project activities have contributed significantly to the information base from which the 1990 Report recommendations in Volume III have been drawn.

CHAPTER 1

Introduction

In 1987, P. L. 100-146, the new Developmental Disabilities Assistance and Bill of Rights Act Amendments came into effect. It mandated consumer input in the policy planning process. One requirement was that each state should do a Consumer Satisfaction Survey:

> Each State Planning Council shall conduct a review and analysis of the effectiveness of, and consumer satisfaction with, the functions performed by, and services provided or paid for from Federal and State funds by each of the State Agencies (including agencies providing public assistance) responsible for performing functions for and providing services to, all persons with developmental disabilities in the State. Such review and analysis shall be based upon a survey of a representative sample of persons with developmental disabilities receiving services from each agency... (Section 122).

A Work Group was formed by the National Association of Developmental Disabilities Councils (NADDC) to explore how the national mandate can be met. The Developmental Disability Center/UAP at Temple University was selected to develop a basic survey instrument and to provide guidelines to assist the State Councils to implement the mandate. (See Appendix A)

The instrument was divided into seven sections:

A. Eligibility/Screening

B. Demographics

C. Services/Satisfaction

D. Independence,
defined as "the extent to which persons with developmental disabilities exert control and choice over their own lives" (P.L. 100-146, Section 102.6)

E. Integration,
defined as "(A) (i) the use by persons of developmental disabilities of the same community resources that are used by and available to other citizens, and (ii) participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens

(B) the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities"
(P.L. 100-146, Section 102.8)

F. Productivity,
defined as, "(A) engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or
(B) engagement by a person with developmental disabilities in work which contributes to a household or community"
(P.L. 100-146, Section 102.7)

G. Support/Services/Assistance Needed

It was recommended that each state should use a sample size of 300 and should follow the standards of modern market research to acquire this sample.

The federal definition of Developmental Disabilities was used to determine who would qualify as being developmentally disabled. This definition describes developmental disability as:

> "a severe, chronic disability of a person which (a) is attributable to a mental or physical impairment; (b) is manifested before the person attains the age of 22; (c) is likely to continue indefinitely; and (d) results in substantial functional limitations in three or more areas of major life activities"
> (P.L. 100-146, Section 102.5)

Procedures

In Mississippi, the Developmental Disability Planning Council was responsible for implementing the mandate. The Research and Training Center for the Handicapped at the University of Mississippi conducted the survey for the Council.

Sampling

The sample of 300 individuals was obtained from four major sources:

1. The Developmental Disability Service Provider Agencies (56%)
2. Mississippi Rehabilitation for the Blind Agency (19%)
3. Mississippi Division of Vocational Rehabilitation (5%)
4. Private agencies receiving federal and/or state assistance (20%)

Letters and fact sheets were mailed to each service provider whose address appeared on lists provided by the Department of Mental Health. The letters described the survey and asked for cooperation from the service providers (see Appendix B). Centers were selected at random from these lists and contacted by telephone to arrange for convenient times to meet with the clients. At smaller centers (n < 60), every single client was included in the sample to avoid selection bias. At larger facilities, every fifth person on an alphabetically ordered list was chosen to participate in the survey.

Participants

To be eligible for the survey, participants must have been disabled before the age of 22. Also, they must require a substantial amount of help in three of seven major life areas. These areas are (1) self care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living; and (7) economic self-sufficiency.

Participants in the survey came from diverse residential settings such as institutions, group homes, supervised apartments and independent living. Care was also taken to ensure that each geographical region in the state was represented (see Appendix C for interview locations). Each client was personally approached by the interviewers for their consent to be interviewed. Consent was refused by only 0.7% of the clients approached. The rest knowingly and willingly signed a statement of consent (Appendix D).

Of these, 4.6% were unable to complete the survey because they did not meet the federal definition of developmentally disabled. That is, they did not require a substantial amount of assistance in three of the seven major life areas and/or were disabled after age 21. Each participant who completed the survey was given a certificate of appreciation (Appendix E).

Data Collection

Each interview was conducted face-to-face with the participant and took an average of one hour to complete, ranging from a minimum of 30 minutes to a maximum of 2 1/2 hours. The two interviewers were both graduate students at the University of Mississippi who worked essentially full time on the project.

For the sake of accuracy as far as the mentally retarded individuals were concerned, Section A and B on Eligibility and Demographics (Appendix A) were completed by service providers before the interviews. Alternatively, interviewers were given access to clients' records to obtain the data. All this was done after the clients and/or their legal guardians had granted their permission by signing the statement of consent (Appendix D).

Results

Data obtained from the survey was analyzed by Temple University using their Program. The following six chapters will present a descriptive discussion of the results of the analysis. The length of the questionnaire makes it impractical to report every response to every question at length. Therefore, these chapters will only summarize the results. Where appropriate, results will be presented in the form of graphs or tables.

The discussion will be organized along the lines of the survey instrument, that is:

Chapter 2.	Section A & B:	Sample Characteristics
Chapter 3.	Section C:	Services Received
Chapter 4.	Section D:	Independence
Chapter 5.	Section E:	Integration
Chapter 6.	Section F:	Productivity
Chapter 7.	Section G:	Services Needed

CHAPTER 2

Sample Characteristics

This chapter is a description of the sample of 300 individuals involved in this survey. It will include a breakdown of primary and secondary diagnoses of the individuals. Demographic factors such as their age, sex, race, and marital status are also included. The final section will describe their functional capabilities.

Primary and Secondary Diagnoses

Of the 300 individuals in the sample, 222 (74.0%) were diagnosed as mentally retarded, and 76 (25.3%) were physically disabled (see Figure 1). There were two missing cases (0.7%). The physically disabled are further broken down by categories. Of the 76 physically disabled individuals, 56 (73.7%) were diagnosed as legally or totally blind, three (3.9%) have cerebral palsy and four (5.3%) are deaf. Six (7.9%) have spinal cord injuries, four (5.3%) have spina bifida and one (1.3%) each has the primary diagnosis of epilepsy, head injury and orthopedic impairments.

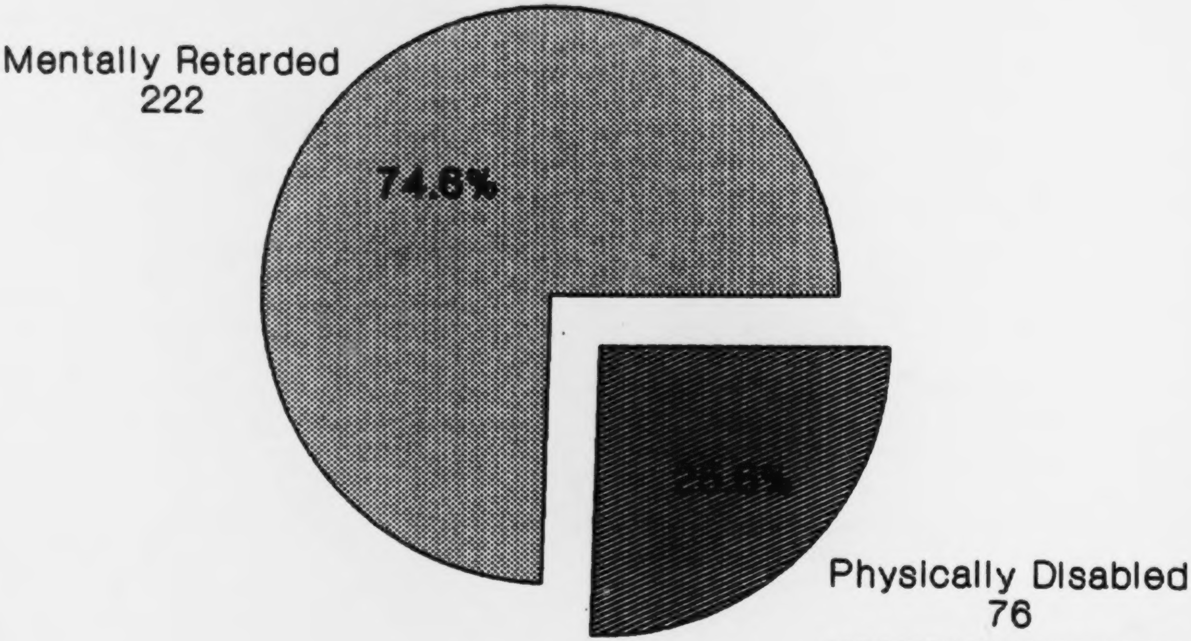
Many of these individuals are multi-handicapped. One hundred and seventy (56.7%) report at least one secondary disability. Table 1 shows the number and percentage of individuals with their secondary disability.

Table 1

Secondary Disabilities

Disability	Count (Percentage)
Autism	16 (5.6%)
Blindness	4 (1.4%)
Cerebral Palsy	15 (5.2%)
Cystic Fibrosis	1 (0.3%)
Deafness	15 (5.2%)
Emotional Disorders	14 (4.9%)
Epilepsy	46 (16.1%)
Head Injury	4 (1.4%)
Mental Retardation	22 (7.7%)
Orthopedic Impairments	2 (0.7%)
Speech Impairments	22 (7.7%)
Health Problems	50 (17.5%)
Behavior Problems	18 (6.3%)
Other	29 (10.1%)

Figure 1
Primary Diagnoses



Blind = 56 (73.7%)
Cerebral Palsy = 3 (3.9%)
Deafness = 4 (5.3%)
Epilepsy = 1 (1.3%)
Head Injury = 1 (1.3%)
Orthopedic = 1 (1.3%)
Spina Bifida = 4 (5.3%)
Spinal Injury = 6 (7.9%)

n=298

Demographic Factors

Age

Only 19 (6.3%) of the respondents were between the ages of 1 - 21 while the majority, 279 (93.0%) were aged above 22 years. There were two (0.7%) missing cases. The mean age is 63.7 with a standard deviation of 18.5. The median age, which in this instance is a more appropriate measure of central tendency due to several extremely high ages, is 34. Thus the respondents were principally adults of working age.

Sex

Both sexes were quite evenly represented with 164 (55.0%) males and 134 (45.0%) females (see Figure 2).

Race

Respondents were predominantly White (203 or 67.9%), with 90 (30.1%) Blacks, and only one (0.3%) Hispanic, one Chinese, one Vietnamese, one American Indian, and two (0.7%) others (see Figure 3).

Marital Status

Most of the respondents (267 or 89.9%) have never been married, 17 (5.7%) are currently married while 13 (4.4%) are separated or divorced.

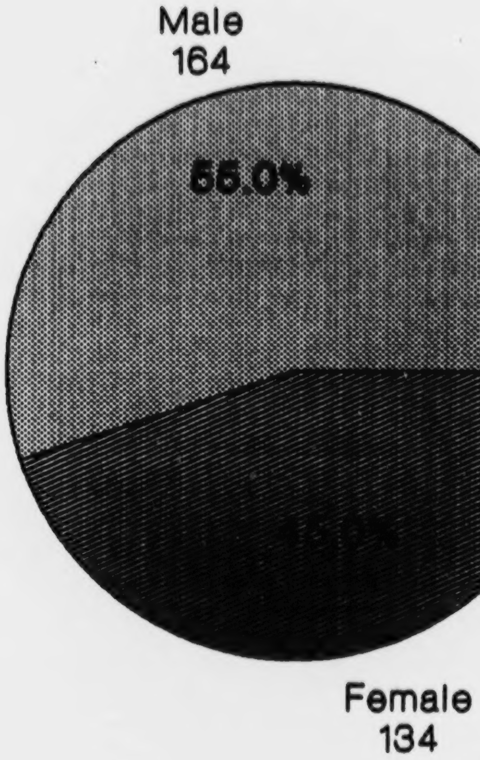
Functional Limitations

This section describes responses to the eligibility questions concerning functional limitations in the seven major life areas.

Self-Care

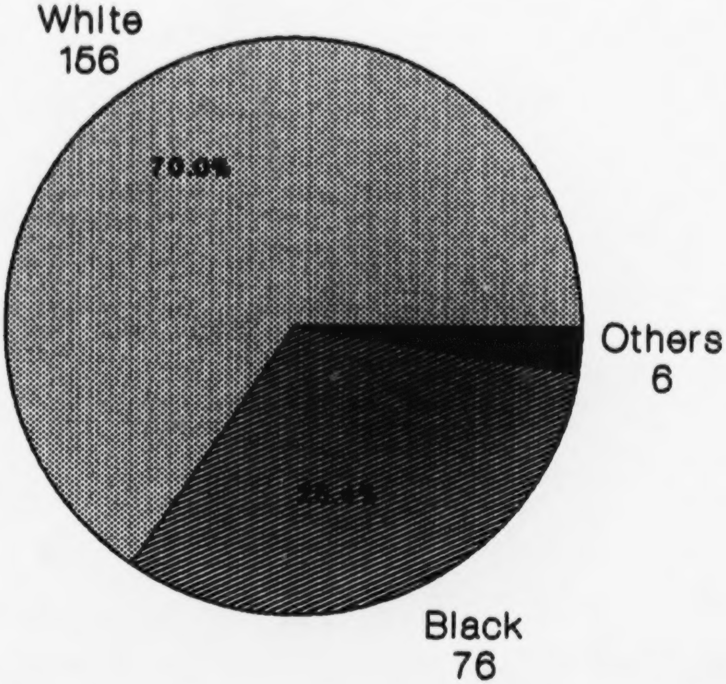
In the area of self-care, 165 (55.4%) reported not needing any help, 99 (33.2%) a little help and 34 (11.4%) a substantial amount of help.

Figure 2
Sex



n=298

Figure 3
Ethnic Groups



n=298

Receptive and Expressive Language

One hundred and sixty-four (54.8%) reported that no help is needed where communication is concerned, 79 (26.4%) needed a little help and 56 (18.7%) needed a lot of help.

Learning

Sixty-nine (23.1%) required no help in learning new skills or behaviors, 112 (37.5%) a little help and 118 (39.5%) a lot of help.

Mobility

A majority of the respondents (259 or 86.6%) reported not needing any help from people or assistive devices in moving from place to place. Only 28 (9.4%) needed a lot of help and 12 (4.0%) a little help.

Self-Direction

In contrast to mobility, a majority of the respondents (249 or 83.6%) said they needed a lot of help with managing their lives, making decisions, and protecting their own interests. Only 12 (4.0%) required no help and 37 (12.4%) a little help.

Capacity for Independent Living

Once again, a large majority of the respondents (275 or 92.0%) reported needing a substantial amount of help in this area. Only 3 (1.0%) required no help at all, and 21 (7.0%) required a little help.

Economic Self-Sufficiency

The response to this question is very similar to that of the previous question. Only two (0.7%) reported needing no help whatsoever in maintaining an income sufficient to support themselves. Twelve (4.0%) needed a little help while 284 (95.3%) needed a lot of help.

CHAPTER 3

Services and Satisfaction

This section deals with the respondents' satisfaction with their current life situations and specific programs and services they were receiving at the time of the interview. The first question concerned their current residential setting. A majority (157 or 53.5%) reported satisfaction and would like to continue living where they were. Only nine (3.1%) wanted to stay with some changes. Thirty-five (11.9%) would like to move to a different geographical area while 92 (31.4%) wanted to move to a different setting. Very few (32 or 12.1%) reported dissatisfaction with their jobs. Most (215 or 82.1%) were satisfied while some (15 or 5.7%) felt neutral about their jobs. Concerning transportation, 228 (89.1%) reported that they had no difficulty getting to work. Twenty-eight (11%) had some or a lot of difficulty with transportation.

As for life in general, 191 (64.3%) were very satisfied, while 106 (35.7%) had some or a lot of dissatisfaction with their lives. One hundred and fifty-two (51.7%) were satisfied with the way they spend their spare time, 142 (48.6%) were not altogether satisfied. Most (188 or 63.7%) found it convenient to get around during their spare time. However, quite a large number (107 or 36.4%) reported some transportation problems in this area.

Responses to questions on some specific programs/ services are summarized in Table 2.

Table 2

Services and Satisfaction

Programs/Services	No Experience	Satisfied	Dis-Satisfied
Aid to Families with Dependent Children	275(92.7%)	6(2.1%)	1(0.4%)
Vocational Rehabilitation	105(38.5%)	106(38.8%)	15(5.5%)
Education	22(7.6%)	225(87.9%)	13(4.5%)
Medical Assistance	37(13.2%)	229(81.5%)	13(4.6%)
Mental Retardation/ Developmental Disabilities Program	201(72.8%)	68(24.6%)	7(2.5%)
Independent Living Centers	264(92.0%)	22(7.7%)	1(0.3%)
Supplemental Security Income	49(18.1%)	199(73.4%)	20(7.4%)
Social Security Disability Income	151(97.2%)	107(39.2%)	13(4.8%)
Maternal and Child Health	279(97.2%)	8(2.8%)	0(0.0%)
Crippled Children's/ Special Health Service	265(94.0%)	17(6.0%)	0(0.0%)
Community Mental Health Services	209(73.9%)	73(25.8%)	1(0.3%)
HUD Section 8 Rent Certificate	276(96.5%)	8(2.8%)	0(0.0%)

The following tables summarize responses to questions about services that the respondents were receiving at the time of the interview. Services that were being received by less than 10% of the respondents will be excluded from the report. An exception is made in the case of residential services because the residential settings of the individuals were so diverse.

Table 3

Case Coordination Services

Service	Number (%) Receiving	Satisfied	Dis-Satisfied
Assessment/IPD	47(15.6%)[1]	44(93.6%)[2]	3(6.4%)[2]
Case Management	158(52.7%)	147(93.1%)	11(6.9%)

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[1] In this and all subsequent tables in this section, this is shown as a percentage of the total sample of 300 respondents.

[2] These are shown as a percentage of those who were receiving the service at the time of the interview.

Table 4

Residential Services

Service	Number (%) Receiving	Satisfied	Dis-Satisfied
Institution	19(6.3%)	14(73.7%)	5(26.3%)
Nursing Home	1	1(100%)	0(0.0%)
Group Home Apartments	88(29.3%)	80(90.9%)	8(9.1%)
Supervised Apartments	34(11.3%)	28(82.3%)	6(17.6%)
Room and Board Domiciliary Care	15(5%)	12(80%)	3(20%)
Substitute/Foster Family Care	18(6%)	17(94.4%)	1(5.6%)
Homemaking Assistance/Training	37(12.3%)	34(91.9%)	3(8.1%)

Table 5

Vocational Services

Service	Number (%) Receiving	Satisfied	Dis-Satisfied
Work Activities/ Prevocational	192(64%)	180(93.7%)	12(6.3%)
Sheltered Employment	69(23%)	49(71.0%)	20(29.0%)
On-site aide/ Attendant	64(21.3%)	62(97.9%)	2(3.2%)

Table 6

Health Services

Service	Number (%) Receiving	Satisfied	Dis-Satisfied
Hospitals	83(27.7%)	73(88.0%)	10(12.0%)
General Medical Services	174(58.8%)	164(94.3%)	10(5.7%)
Dental Service	132(44.0%)	123(93.2%)	9(6.8%)
Health Insurance (Private)	77(25.7%)	75(97.4%)	2(2.6%)
Medicaid	165(55.0%)	152(92.1%)	13(7.8%)
Payment for Provision of Medication	135(45.0%)	115(85.2%)	20(14.8%)

Table 7

Individual Support Services

Service	Number (%) Receiving	Satisfied	Dissatisfied
Respite Care	39(13.0%)	37(94.9%)	2(5.1%)
Mental Health/ Counselling Service	54(18.0%)	48(88.9%)	6(11.1%)
Occupational Therapy	34(11.3%)	30(88.2%)	4(11.8%)
Community Living Assistance or Training	47(15.7%)	45(95.7%)	2(4.3%)
Income Assistance	187(62.3%)	171(91.4%)	16(8.6%)
Food Assistance/ Food Stamps	64(21.3%)	53(82.8%)	11(17.2%)
Self Help/Support Group	32(10.7%)	30(93.8%)	2(6.2%)
Financial Management Service	70(23.3%)	67(95.7%)	3(4.3%)
Community Support Service	32(10.7%)	29(90.6%)	3(9.4%)

Table 8

Transportation Services

Services	Number % Receiving	Satisfied	Dis-Satisfied
Transportation to and from work	229(76.3%)	218(95.2%)	11(4.8%)
Transportation to and from non-daily activities	234(78.0%)	208(88.9%)	26(11.1%)
Transportation for leisure time (weekdays)	203(67.7%)	147(72.4%)	56(27.6%)
Transportation for leisure time (weekends)	214(71.3%)	158(73.8%)	56(26.2%)
Transportation Training	54(18.0%)	48(88.9%)	6(11.1%)

Table 9

Recreation/Leisure Services

Services	Number % Receiving	Satisfied	Dis-Satisfied
Recreation/Leisure Services	139(46.3%)	98(70.5%)	41(29.5%)

Of all the services that are being provided by the State of Mississippi, very few appear to be utilized by a majority of the respondents. Only nine programs are being used by more than 50% of the respondents. These programs are case management services, work activity centers, general medical services, medicaid, income assistance, and four transportation services.

However, respondents who are receiving the services appear to be generally satisfied with them. Only seven of the programs had more than 20% of the respondents voicing dissatisfaction. These programs are institutional care, room and board domiciliary care, sheltered employment programs, mental health/counselling services, transportation for leisure time (weekdays and weekends), and recreational services.

Where dissatisfaction is voiced, the three reasons most frequently given for dissatisfaction were 1. they are not receiving enough; 2. the service is not suited to individual needs, and 3. the quality of the service is poor. Other reasons given include understaffing, the service being too expensive, not helping, and not respecting their personal dignity. The major reasons for dissatisfaction are summarized in Table 10.

Table 10

Major Reasons for Dissatisfaction[1]

Services	Not Receiving Enough	Reasons Not Suited to Individual Needs	Poor Quality
Coordination Services	6(42.8%)	0(0.0%)	1(7.1%)
Residential Services	4(15.4%)	7(26.9%)	1(3.8%)
Vocational Services	2(5.9%)	7(20.6%)	4(11.8%)
Health Services	16(25.0%)	3(4.7%)	7(10.9%)
Individual Support Services	31(63.3%)	3(6.1%)	12(24.5%)
Transportation Services	67(43.2%)	47(30.3%)	4(2.6%)
Recreational/ Leisure Services	25(61.0%)	1(2.4%)	1(2.4%)

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[1] The percentages in this table are computed based on a total of everyone who voiced dissatisfaction with that service.

CHAPTER 4

Independence

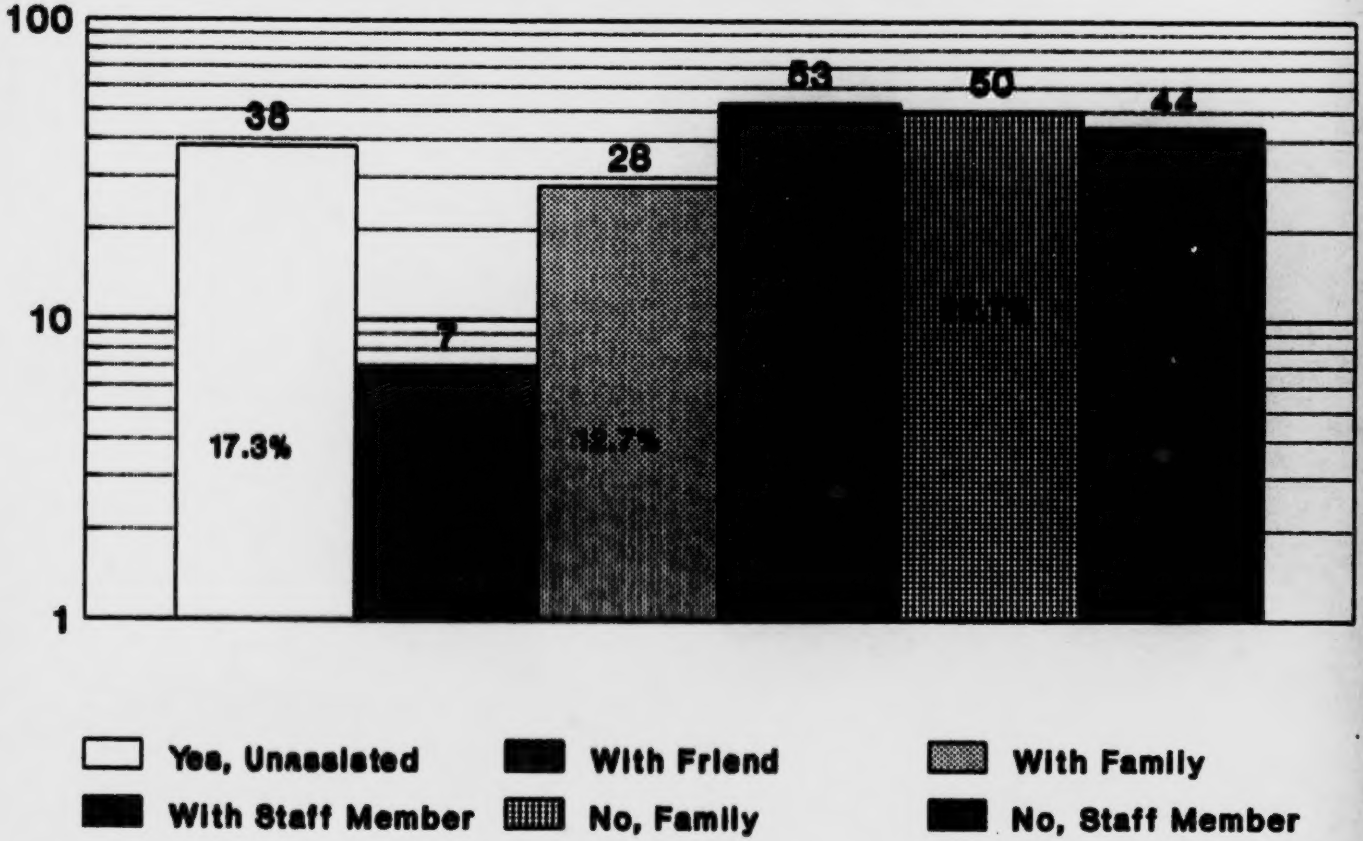
Choice of Living Situations

The majority of the respondents reported not owning their own homes. Only 33(11.2%) owned the house, apartment or trailer where they were living. Thirty-eight (17.3%) chose their place of residence unassisted. Seven (3.2%) did it with the assistance of a friend, 28 (12.7%) with the assistance of a family member, and 53(24.1%) with the assistance of a staff member. Forty-three percent of the respondents reported having no choice whatsoever in their place of residence. Fifty (22.7%) had their place of residence chosen for them by their family while 44 (20.0%) said staff members made the decision for them (see Figure 4).

As for the residential support staff, only 16 (5.3%) said they had any say in choosing them. Some (57 or 19.0%) said the decision was made by staff members or someone else. The majority (227 or 75.7%) did not know who chose their residential support staff (see Figure 5).

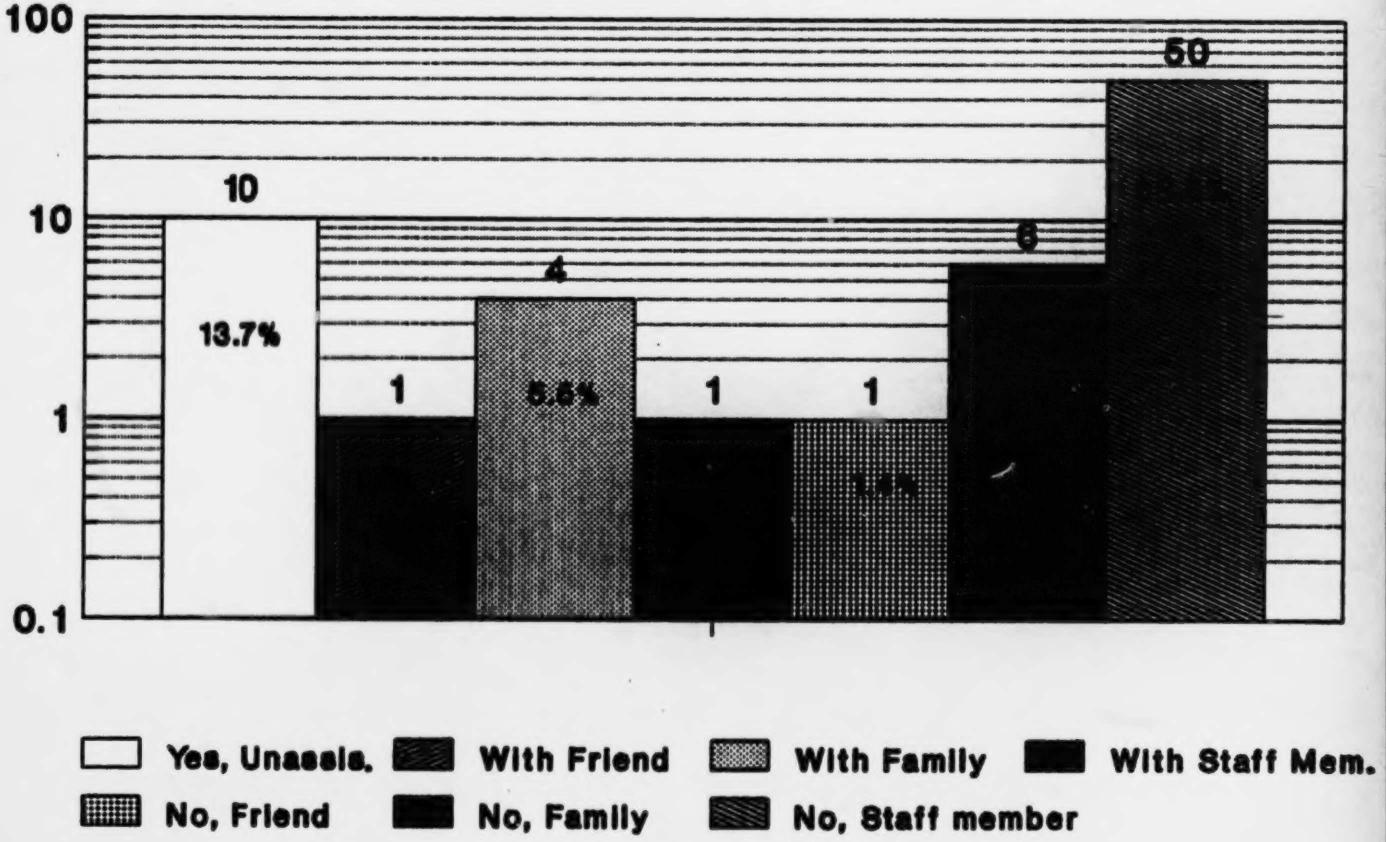
The figures are somewhat better for choice of roommates. Of those who had roommates, 54 (46.2%) chose their own roommates, some with assistance from friends, family or staff. Sixty-three (53.9%) said the decision was made by staff members, and to a lesser extent, family and friends (see Figure 6).

Figure 4
Choose Place of Residence



n=220

Figure 5
Choose Staff Members



n=73

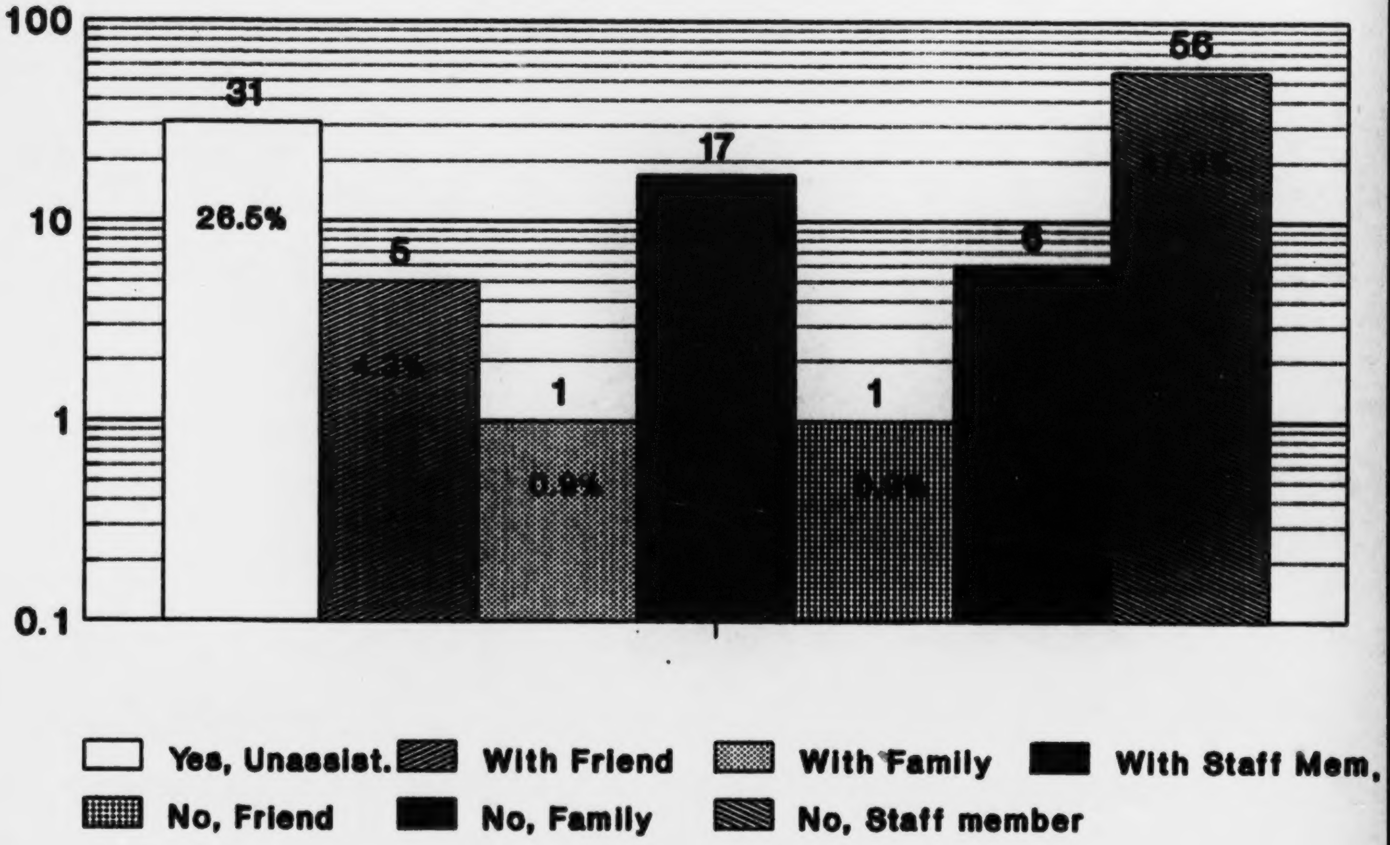
In the area of personalizing their homes, the figures were much better. Two hundred and ten (70.0%) decided for themselves how their homes should be decorated. Only 39 (13.0%) said they had no say in the matter. Fifty-one (17%) said their homes were not decorated (see Figure 7).

Choice of Occupations and Leisure Activities

The survey participants were also asked to respond to questions on how much input they have in choosing their jobs or what they do during weekdays. Keeping in mind that the majority of the respondents (267 or 89%) were adults of working age, this in most cases means a paying job. One hundred and eighty respondents (60%) reported having a choice in what they do on weekdays. One hundred and five (35%) said they did not have any choice. Fifteen (5.0%) were unable to answer the question (see Figure 8).

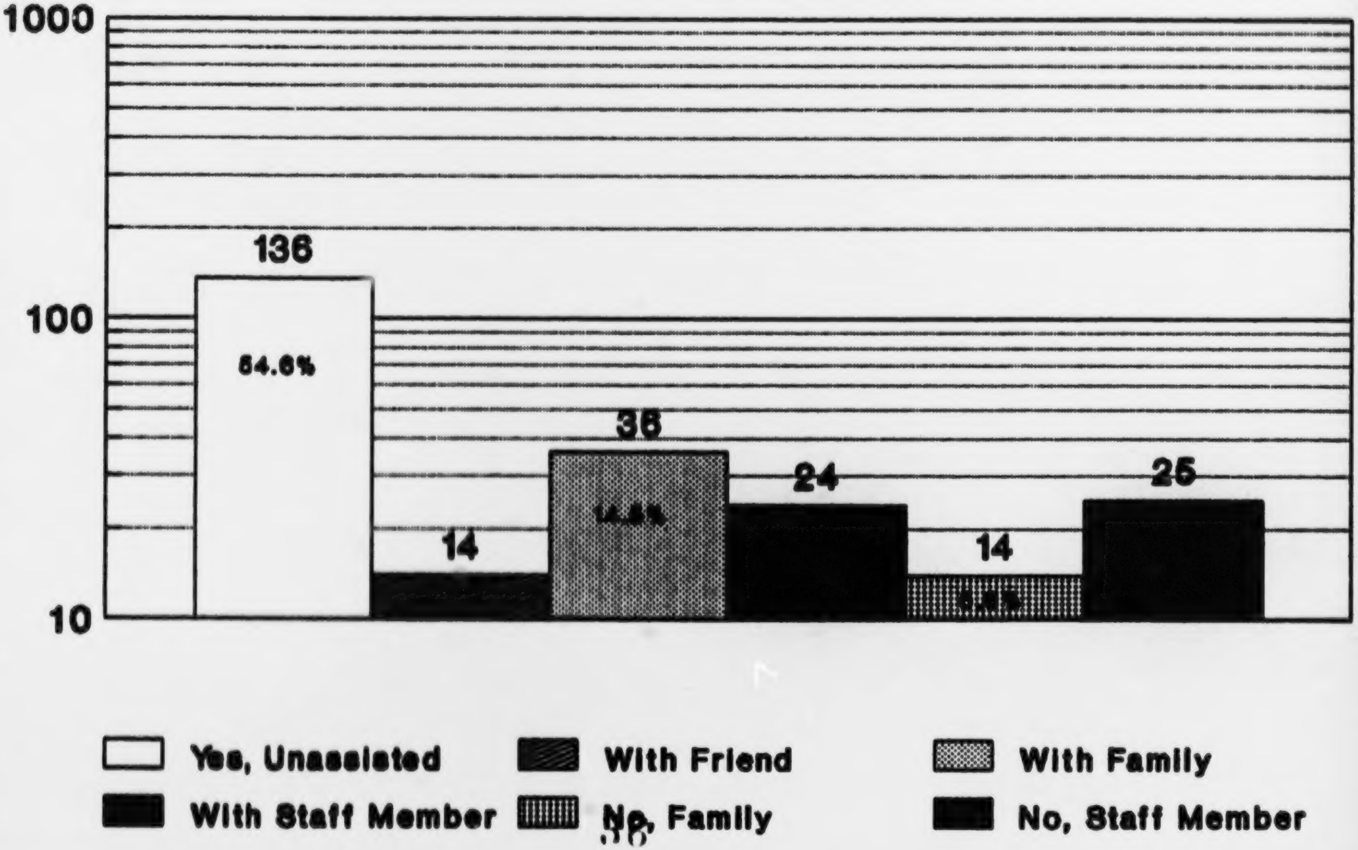
As for leisure activities, 261 (87.0%) said they can choose to do whatever they wish while 42 (14.0%) had no choice. Twelve (4%) did not give an answer (see Figure 9).

Figure 6
Choose Roommates



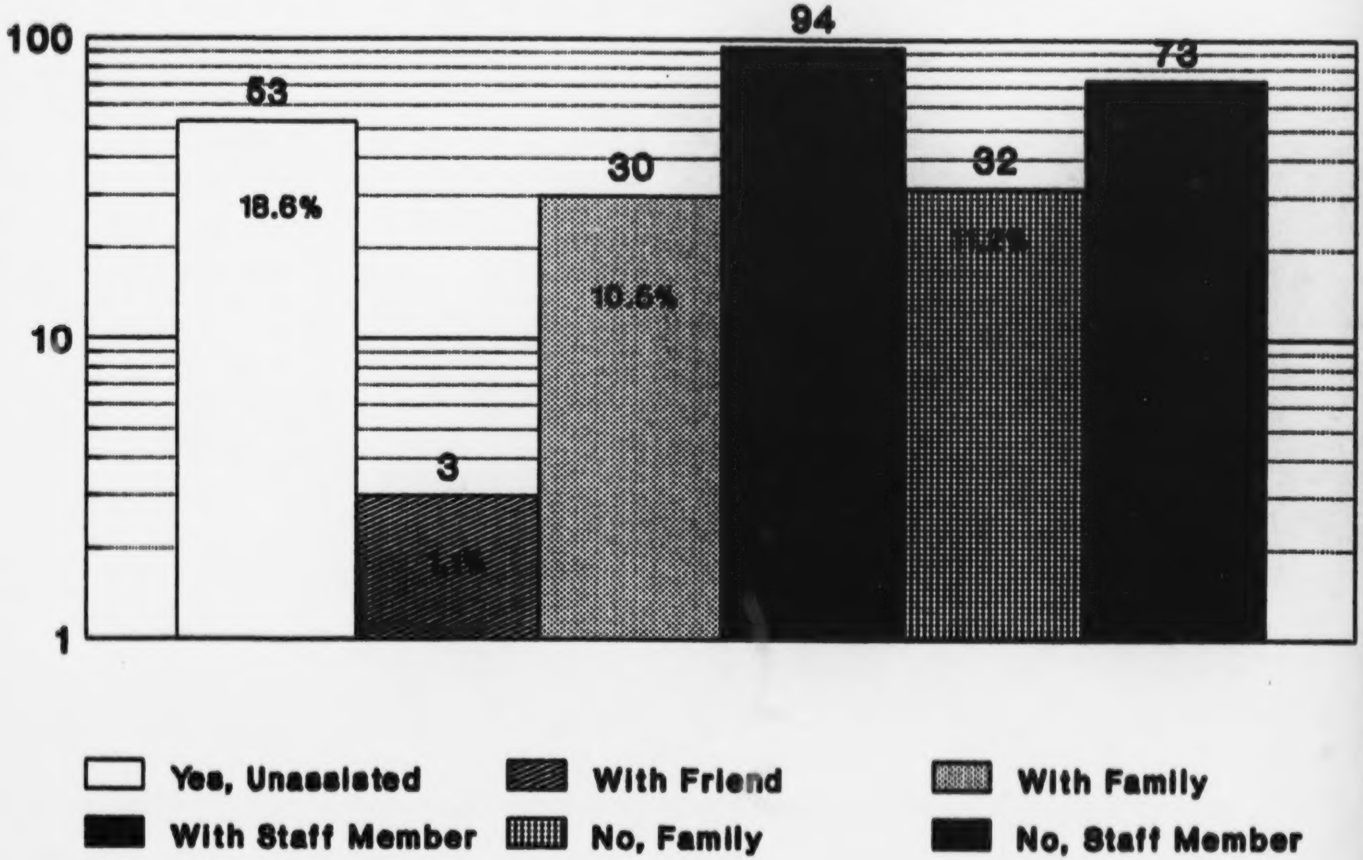
n=117

Figure 7
Decide on Decoration



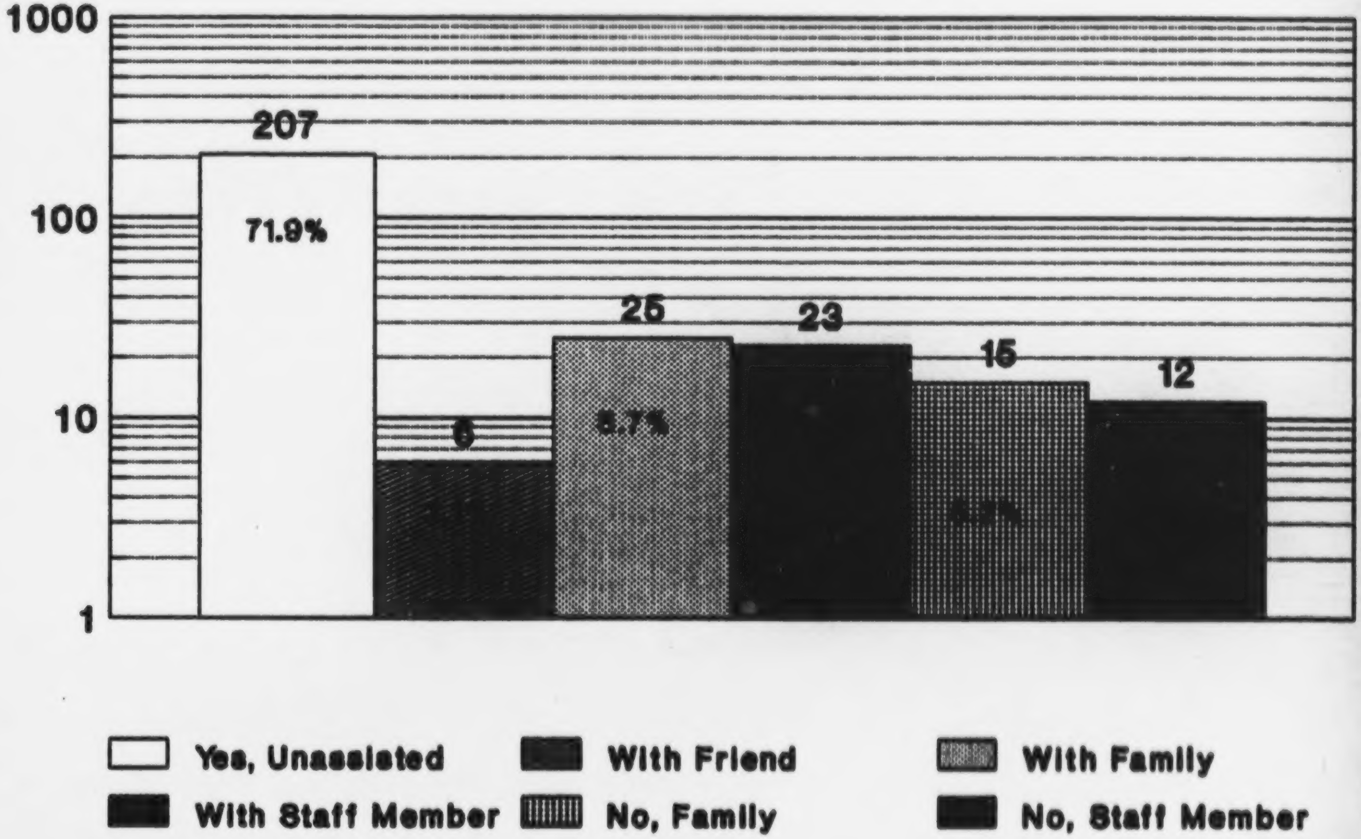
n=249

Figure 8
Choose Day Activity



n=285

Figure 9
Choose Weekend/Evening Activities



n=288

Input in Medical and Financial Matters

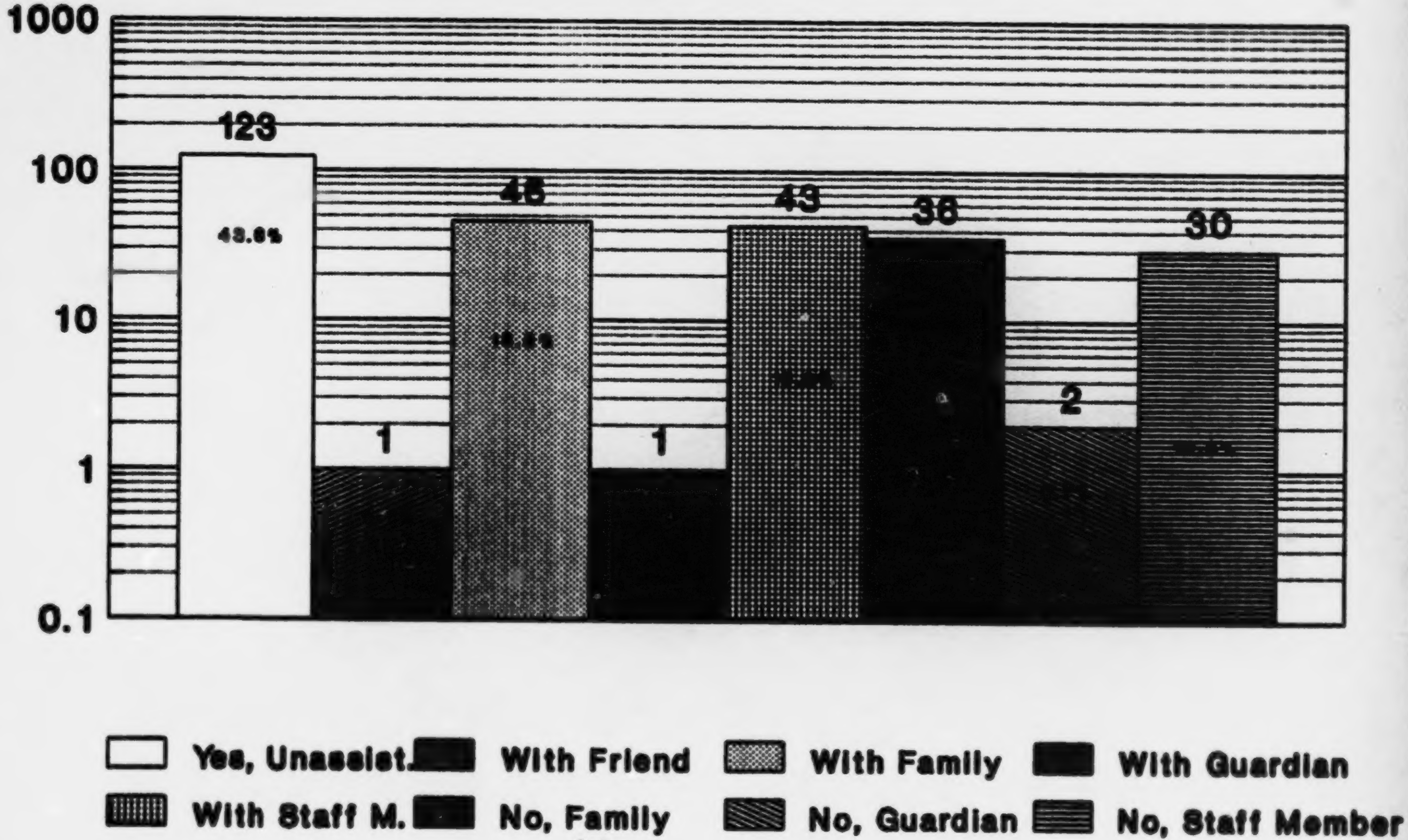
In medical matters, 123 (41.0%) were able to give their own consent for medical care. Ninety-one (30.3%) had to have the assistance of either a family member, legal guardian or staff member. Eighty-six (28.7%) required someone else to give the consent (see Figure 10).

Regarding agencies and organizations that provide support and services, only 48 (10%) chose them unassisted. Fifty-eight (19.3%) needed the assistance of staff, family and friends. One hundred and twenty-eight (42.7%) said they had no choice in the matter. Sixty-six (22.0%) said they had no idea who decides which agencies or organizations they use (see Figure 11).

Only 84 (28.0%) conduct their own banking transactions. Ninety-eight (32.7%) required some assistance in conducting these transactions. The majority of the respondents (118 or 39.3%) did not take part at all. For these respondents, their banking was handled mostly by staff members (50 or 16.7%) and family members (33 or 11.0%) (see Figure 12).

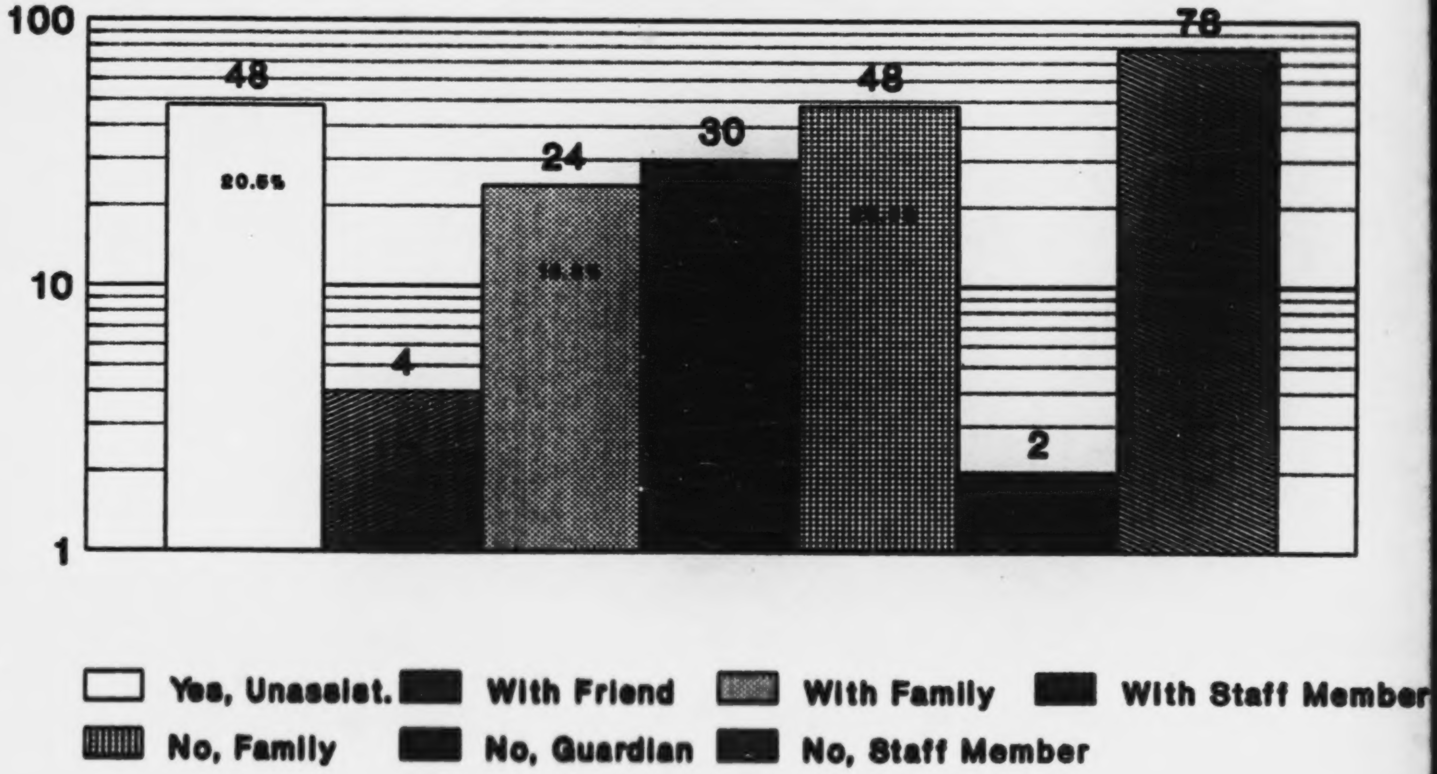
Only 79 (26.3%) paid their bills without assistance. Sixty-six (22.0%) handled their bills with some help from staff members, family, friends and legal guardians. For the majority, 101 (33.7%), staff or family members handled their bills. Fifty-four (18.0%) did not know how their bills are paid or who paid them (see Figure 13).

Figure 10
Give Own Consent For Medical Care



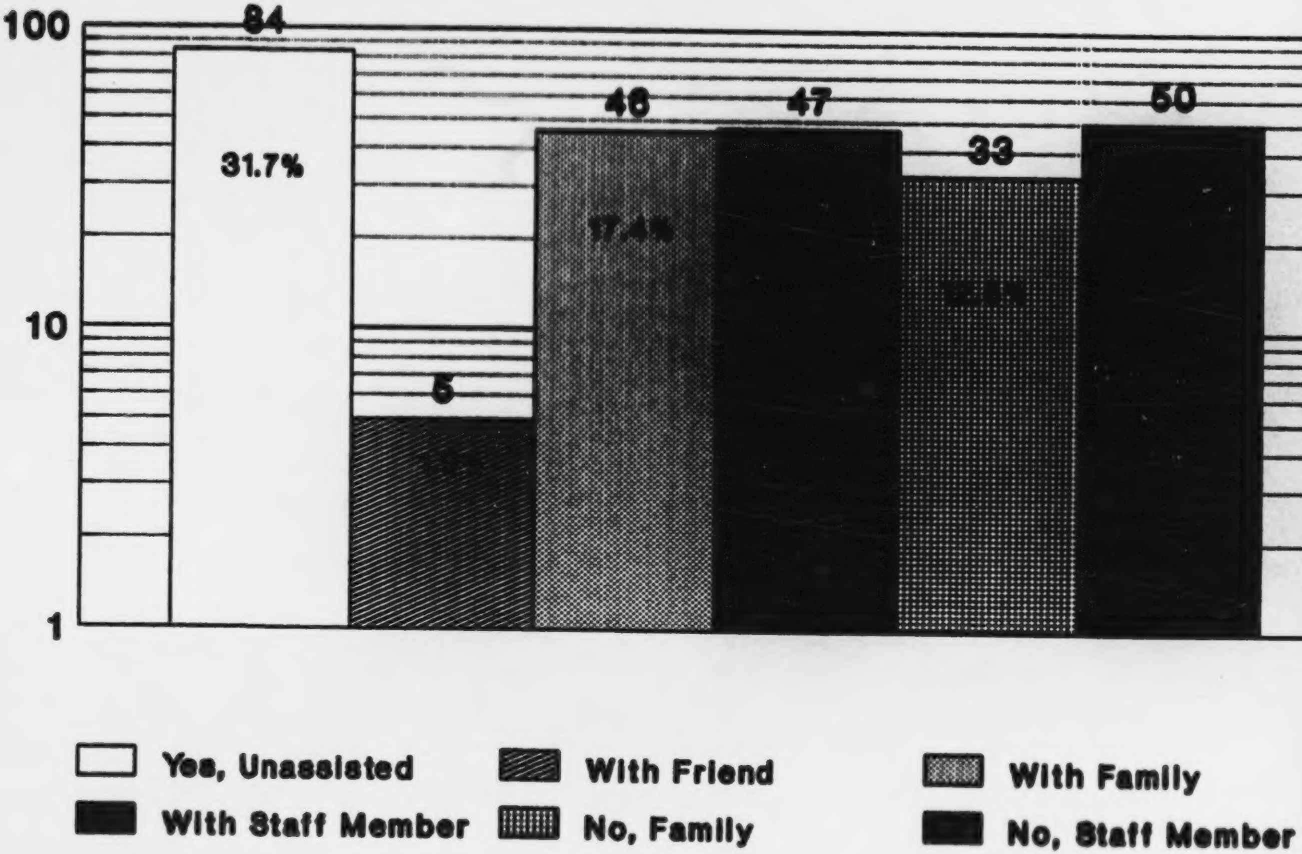
n=282

Figure 11
Choose Support Agencies/Organizations and Services



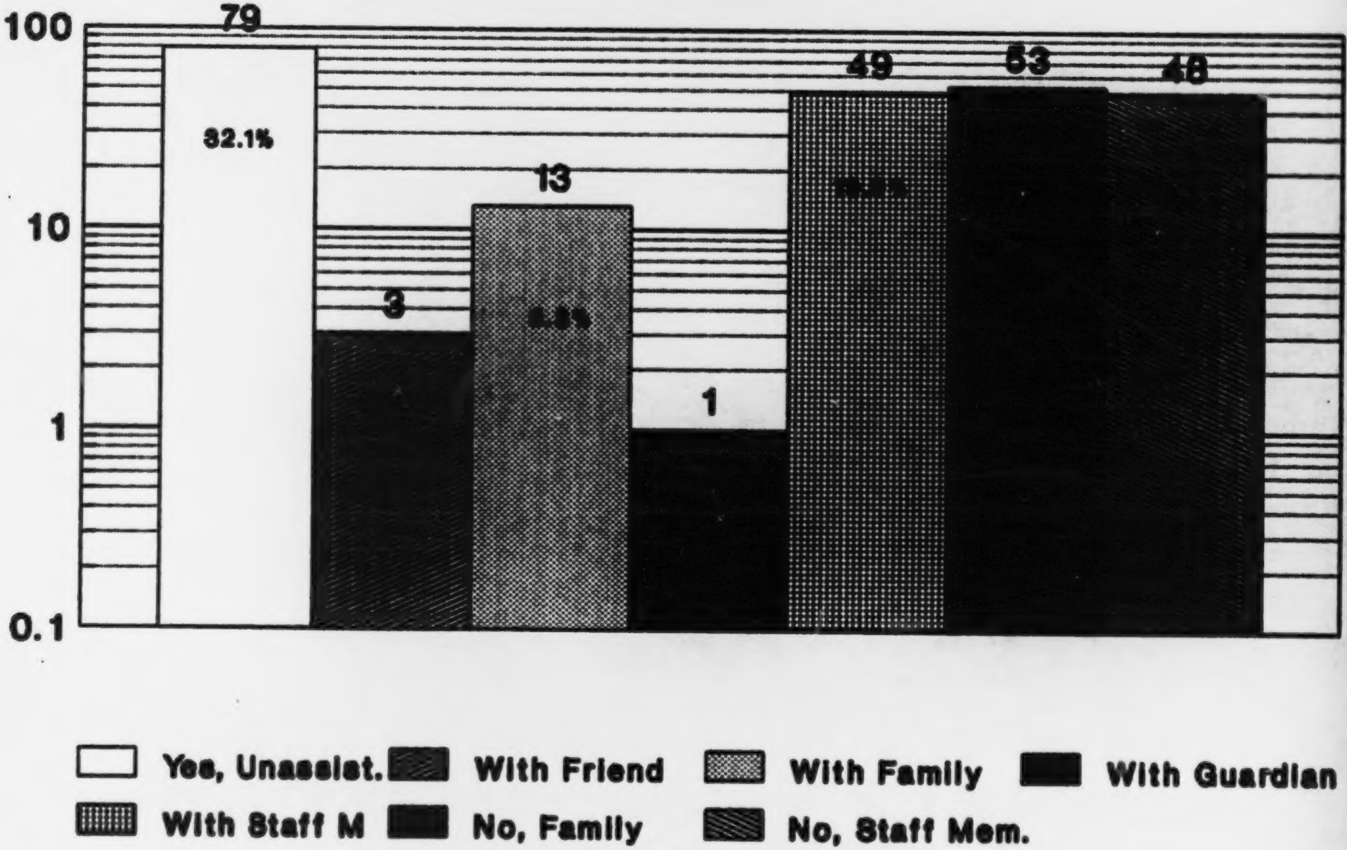
n=234

Figure 12
Conduct on Banking Transactions



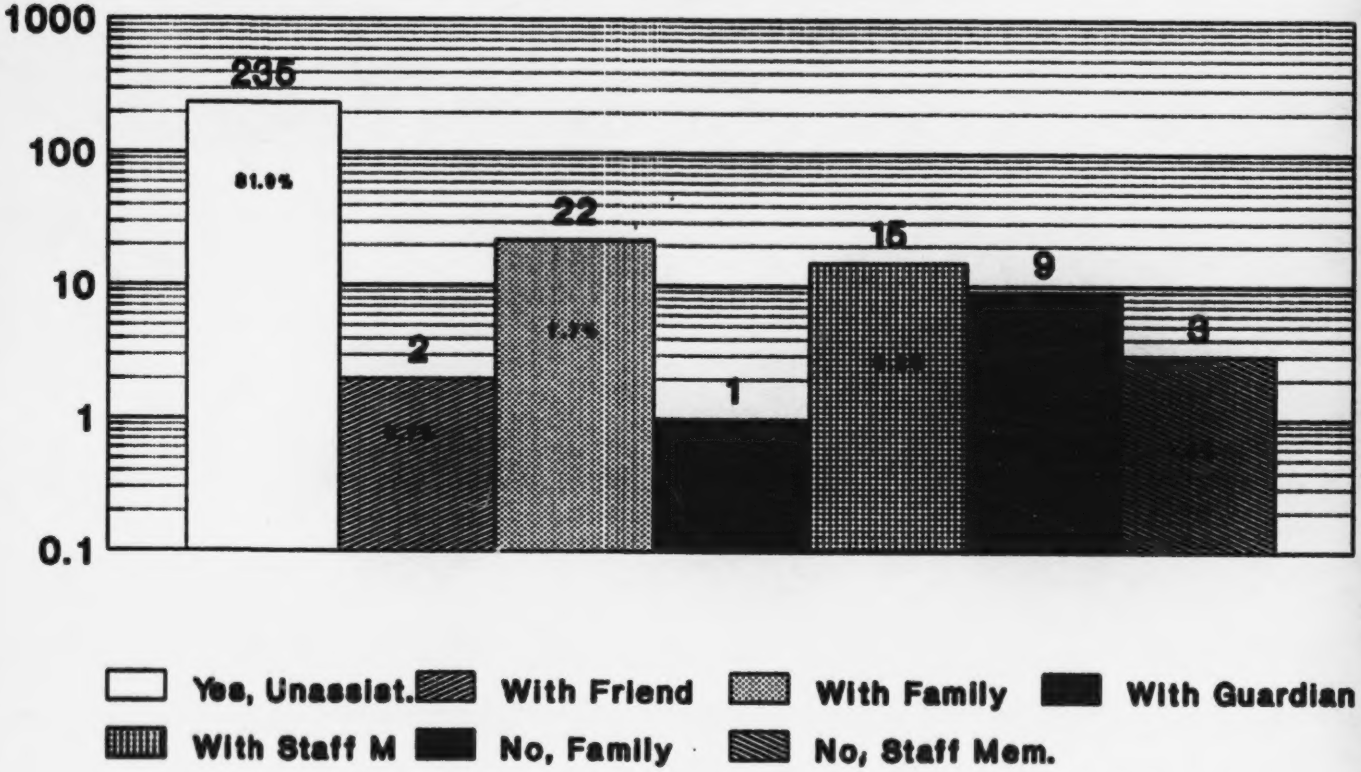
n=265

Figure 13
Pay Bills



n=246

Figure 14
Decide What To Buy With Spending Money



n=287

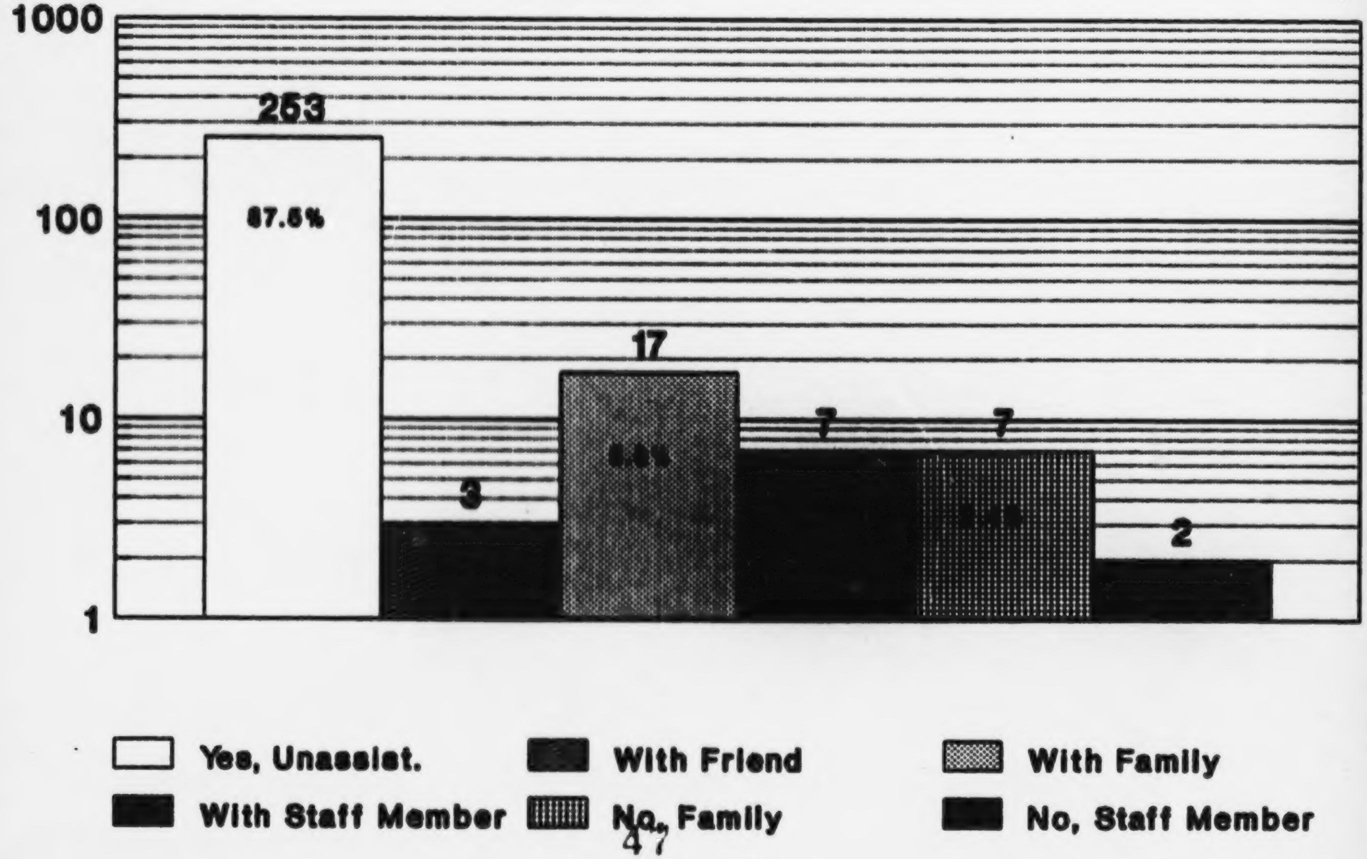
The area where respondents appear to have the greatest amount of choice in financial matters is what they do with their spending money. Here, 239 (79.7%) say they decide without assistance. Forty (13.3%) required some assistance, and only 12 (4%) said they have no choice in the matter. Thirteen (4.3%) reported having no spending money (see Figure 14).

Input in Social Matters

When asked if they chose their own friends and acquaintances, the results are encouraging. The majority, 253 (84.3%), said they chose their friends without assistance. Twenty-seven (9.0%) said family, friends and staff members helped them choose, while nine (0.3%) said they had no choice. Eleven (3.7%) either reported not knowing how their friends were chosen or that they had no friends (see Figure 15).

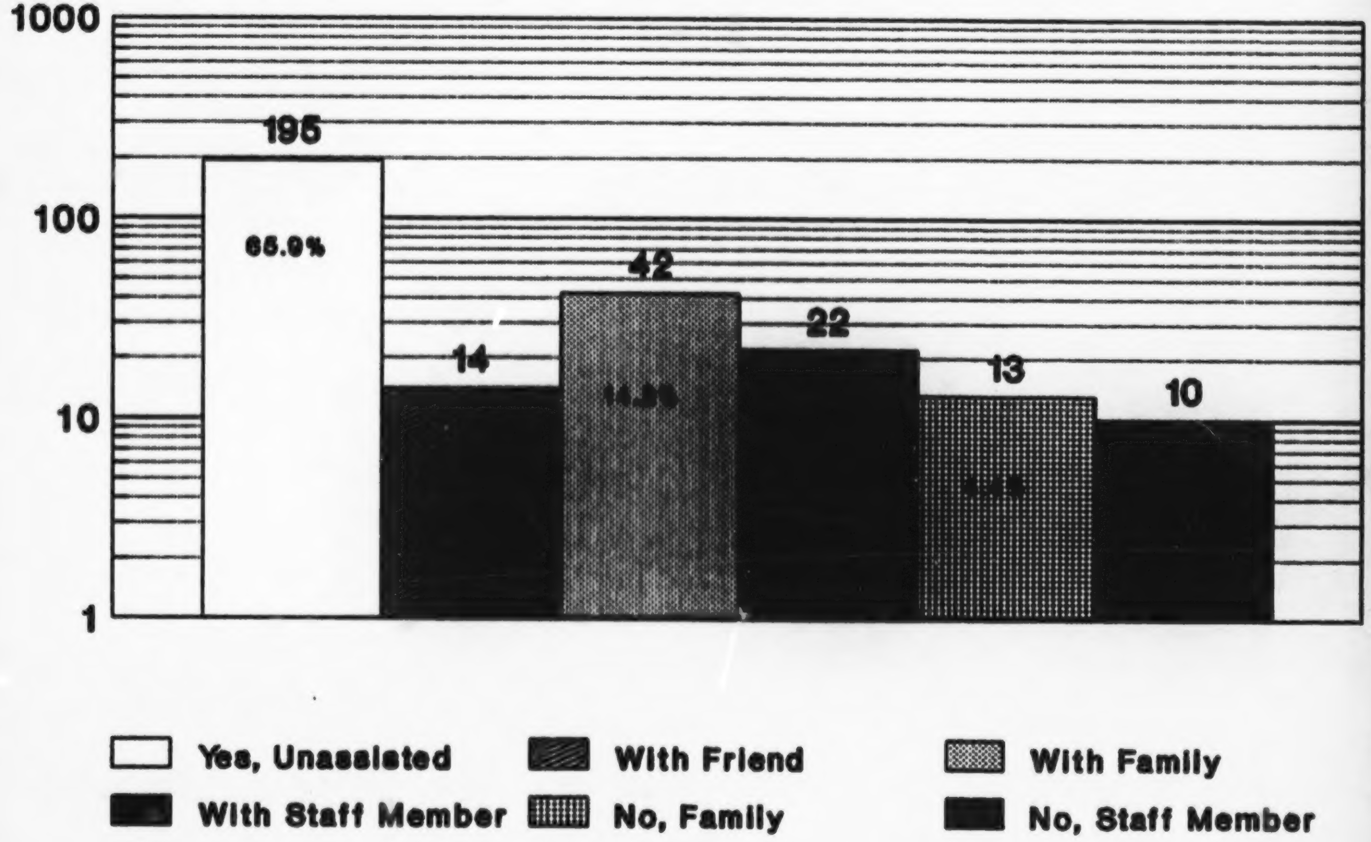
As to the clothes they wear, 195 (65.0%) said they decided what they wear without assistance. Seventy-eight (26.0%) had the assistance of family, staff and friends. Twenty-three (7.7%) had these choices made for them by family and staff members. Four (1.3%) could not answer the question (see Figure 16).

Figure 15
Choose Own Friends



n=289

Figure 16
Choose What Clothes to Wear



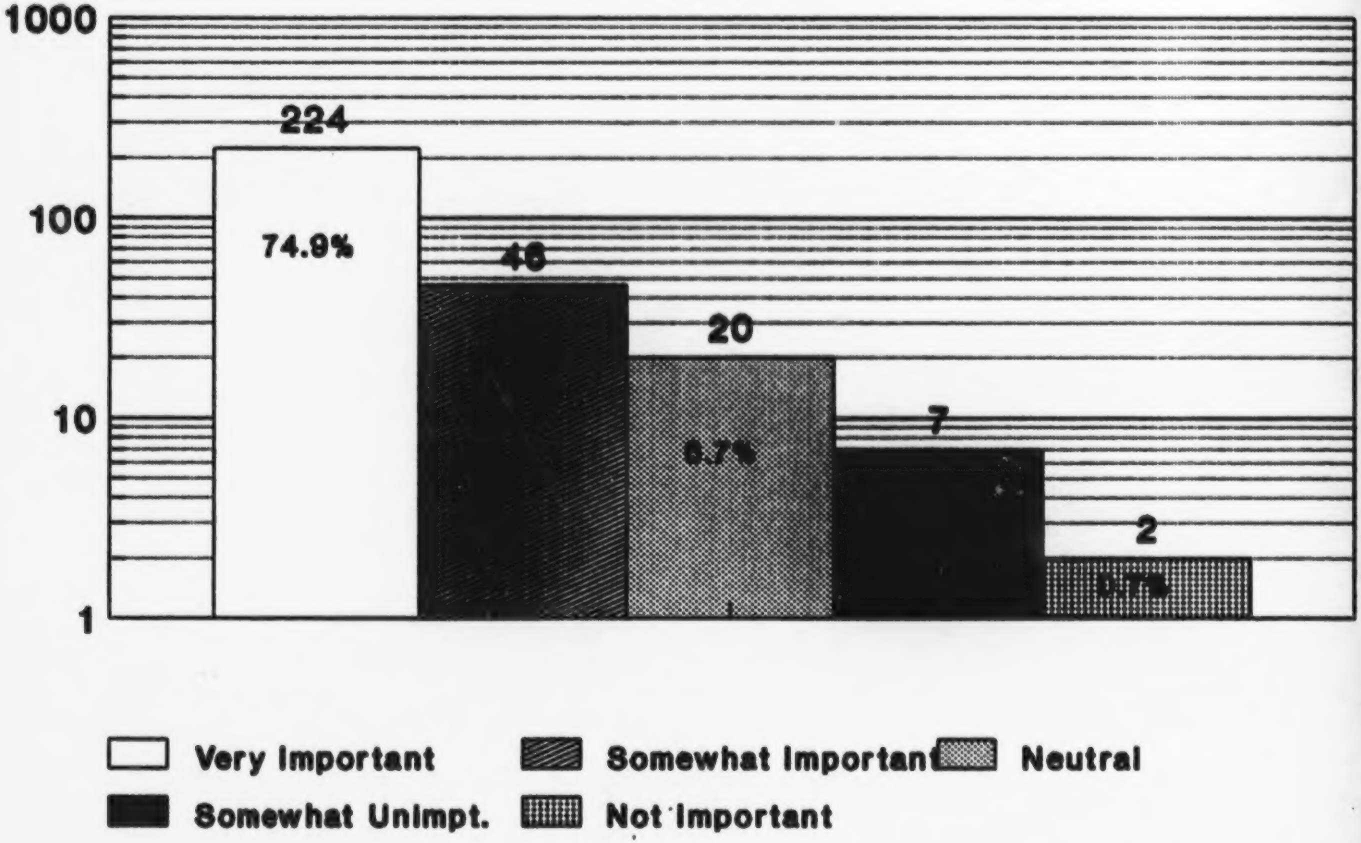
n=296

Independence and Its Importance

When asked to rate their own level of independence, only 47 (15.7%) said they were totally independent, and 12 (4%) said they were not at all independent. The majority 240 (80.0%), rated themselves as being somewhat independent.

Not surprisingly, independence was of extreme importance to the majority of the respondents (224 or 74.7%). Only two (0.7%) said it was not at all important, and 73 (24.3%) said it was only somewhat important (see Figure 17).

Figure 17
Importance Of Independence



n=299

CHAPTER 5

Integration

This section of the survey asked respondents about their participation in community activities. The first question asked whether or not they had voted in the last general election. Of the 293 who were of voting age, 158 (54.0% of the 293) did not vote while 135 (46.1%) did (see Figure 18).

Respondents were then asked to quantify the number of times they participated in seven activities on a weekly to monthly basis. A large percentage (50% and above) indicated that they visited supermarket and churches at least once a week. About 30% to 49.9% responded that they visit their friends, relatives or neighbors, and go to restaurants and shopping centers at least once a week. Between 10% to 29.9% said they go to the bank at least once a week. Only 1% go to a bar at least once a week.

For most of these activities, very few respondents indicated that they never participate in them. Less than 20% said they never visit with their friends, relatives or neighbors, go to supermarkets, restaurants, churches and shopping centers. More than 30% indicated that they never go to a bank. By contrast, an overwhelming majority (90%) had never been to a bar or tavern. A summary of these figures are presented in Table 11. Precise figures can be found on Figures 19 to 25.

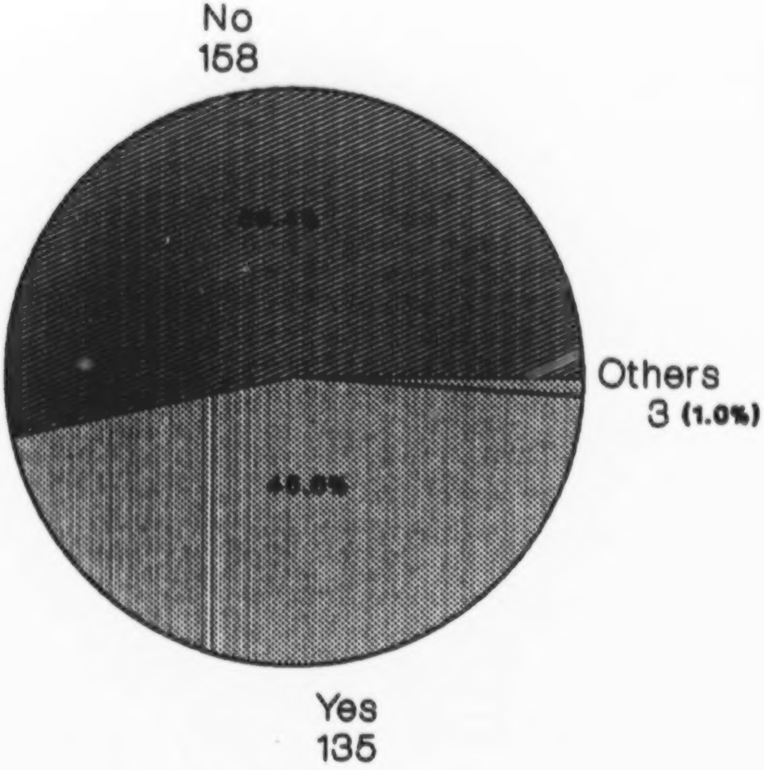
Table 11

Frequency of Participation in Community Activities[1]

Activity	Frequency Once a week and more	Less than once a week	Never
Visit friends/ relatives/ neighbors	147(49.0%)	110(36.7%)	30(10.0%)
Visit supermarket/ food store	150(50.0%)	89(29.7%)	50(16.7%)
Go to restaurant	90(30.0%)	163(54.3%)	34(11.3%)
Go to church	191(63.7%)	54(18.0%)	51(17.0%)
Go to shopping center	106(35.3%)	148(49.3%)	33(11.0%)
Go to bar/ tavern	3(1.0%)	25(8.3%)	262(87.3%)
Go to bank	66(22.0%)	123(41.0%)	99(33.0%)

[1] Percentages in this table will not add up to 100% because of non-responses.

Figure 18
Vote



n=296

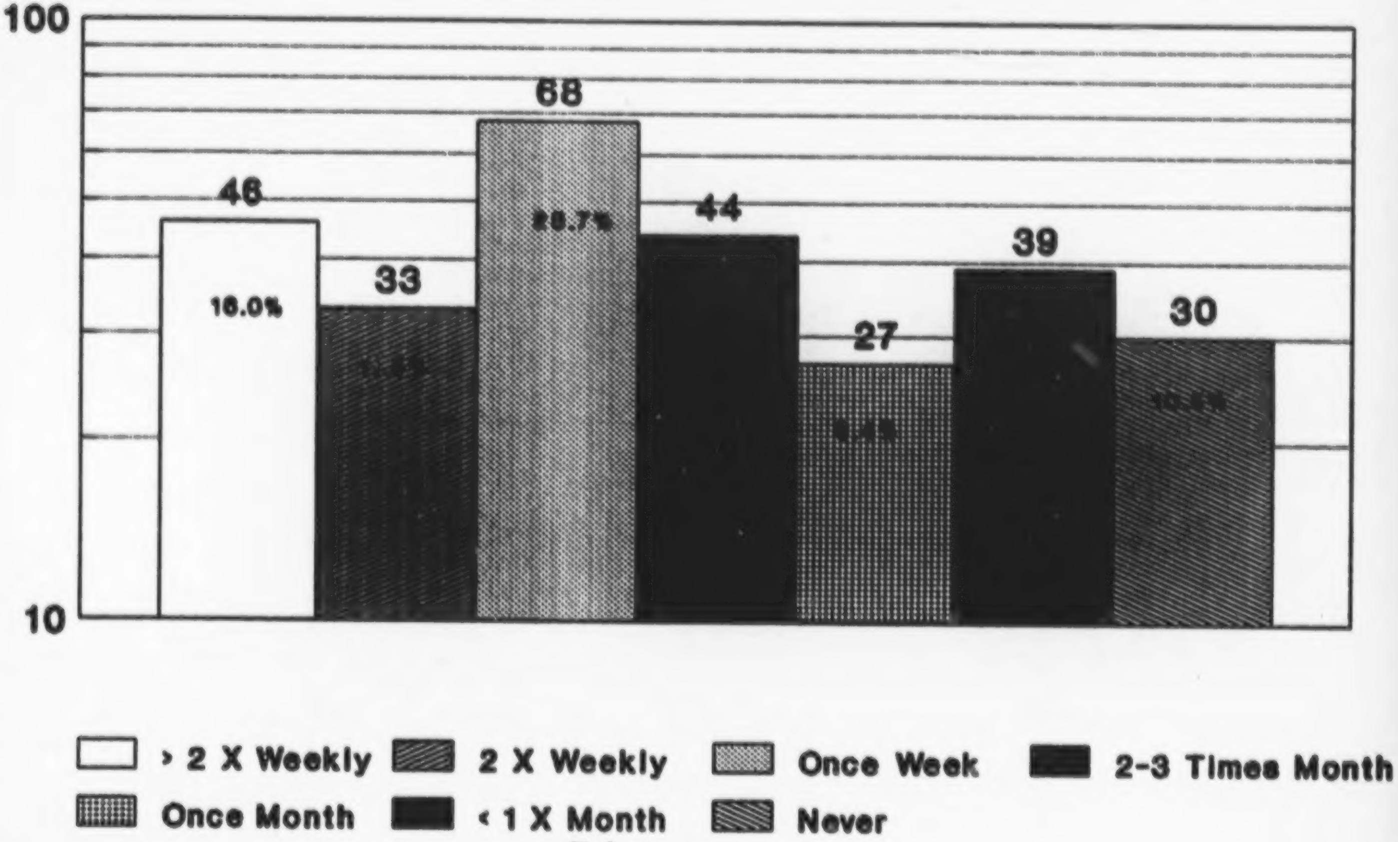
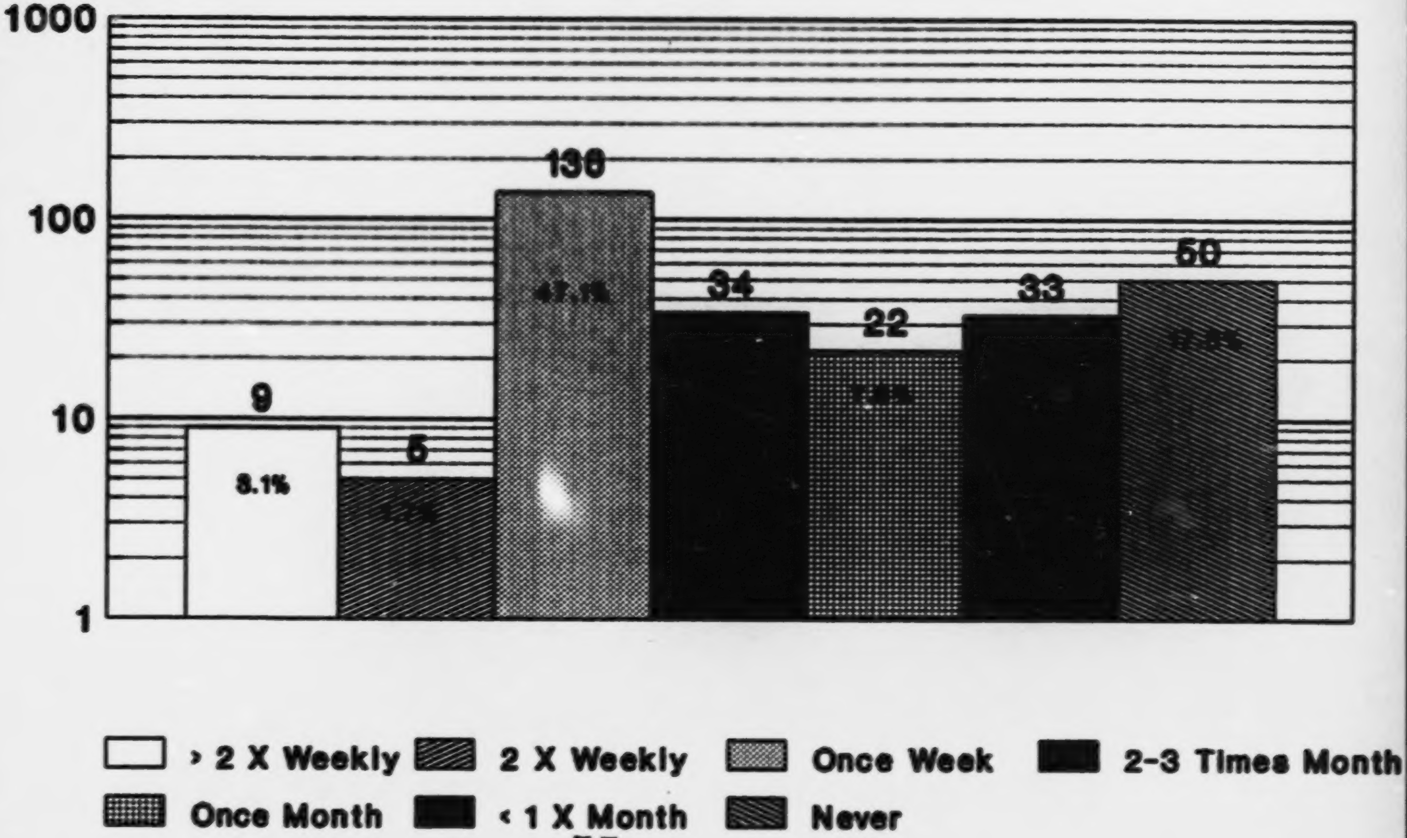


Figure 19
Visit With Friends/Relatives/Neighbors

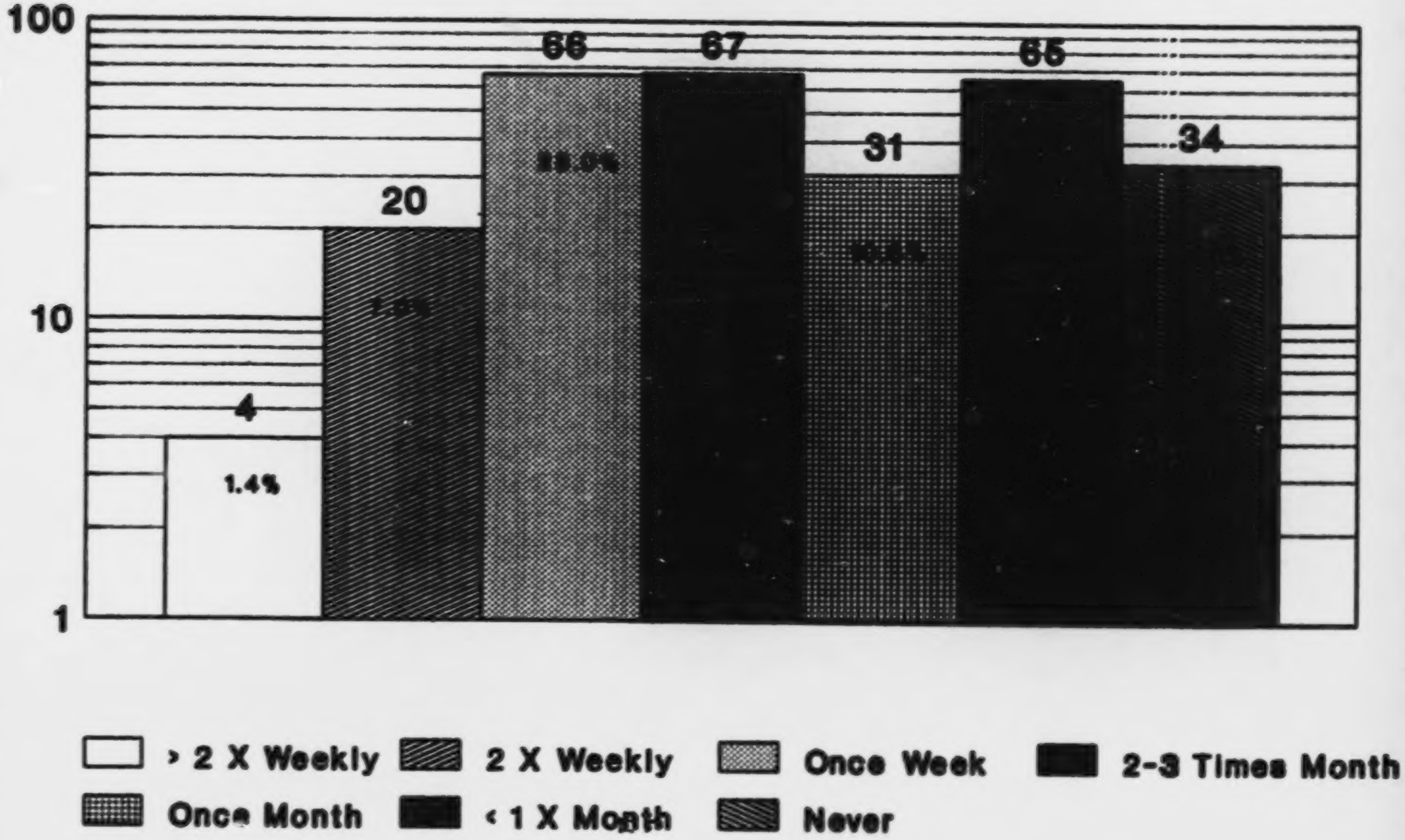
n=287

Figure 20
Visit The Supermarket



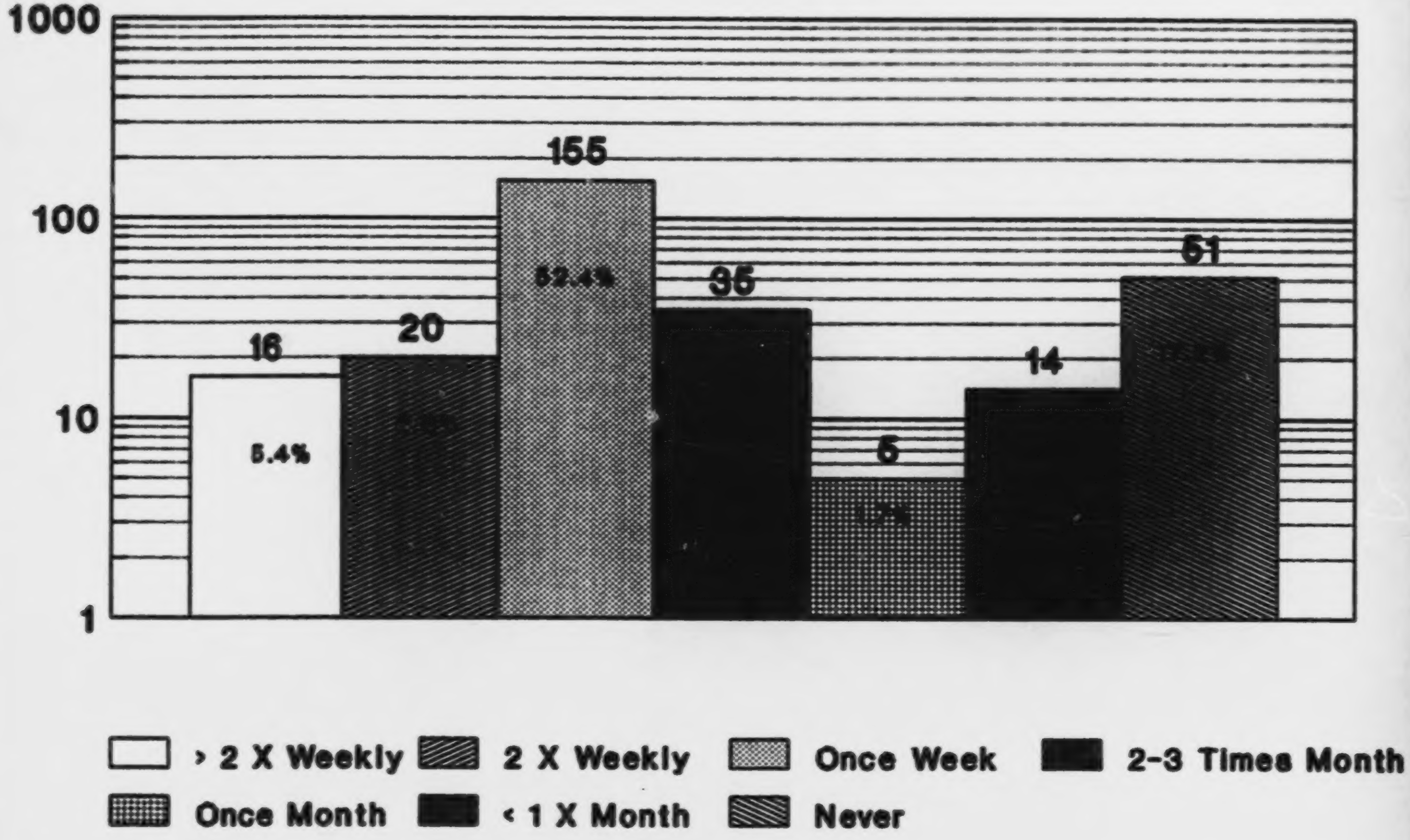
n=289

Figure 21
Go To The Restaurant



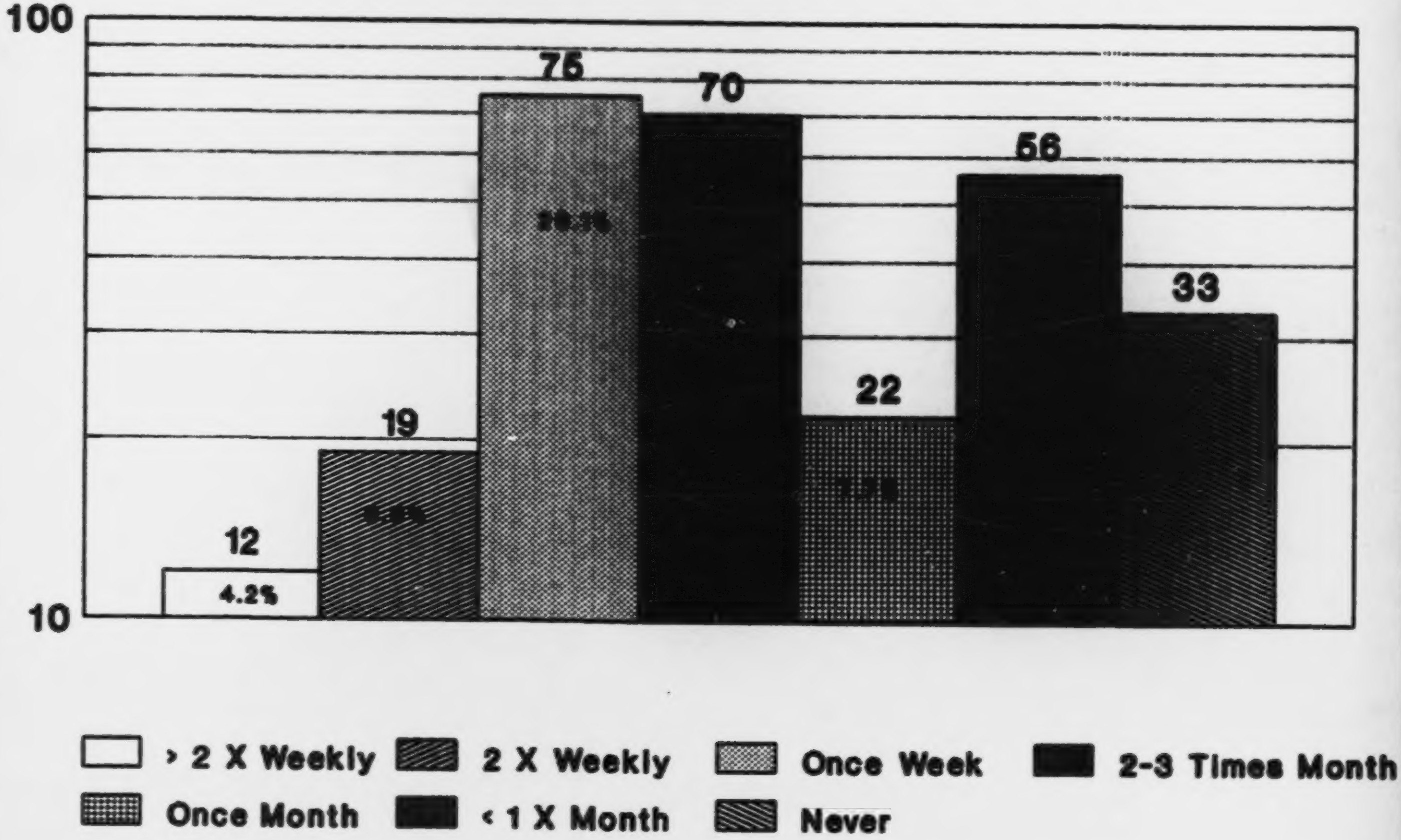
n=287

Figure 22
Go To The Church



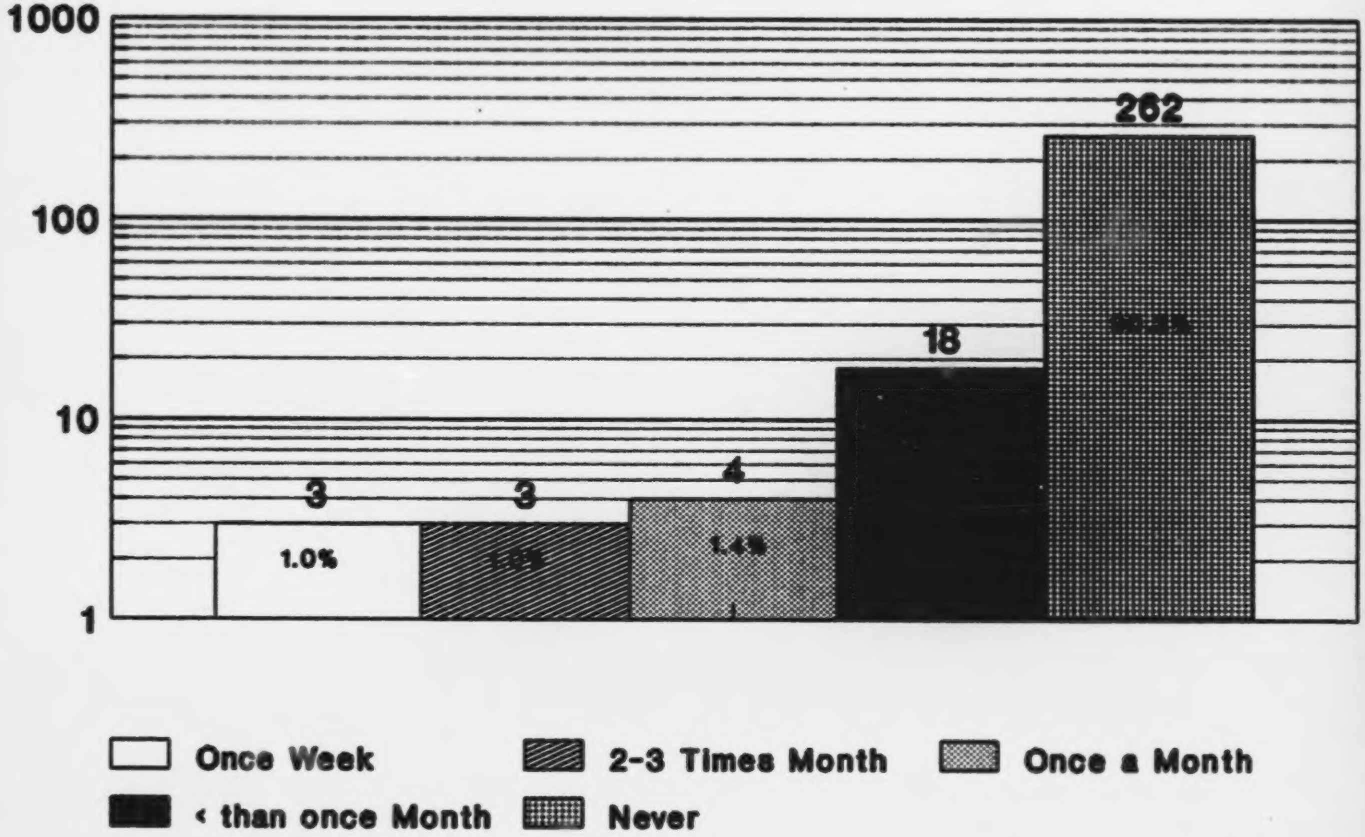
n=296

Figure 23
Go To The Shopping Mall ,etc.



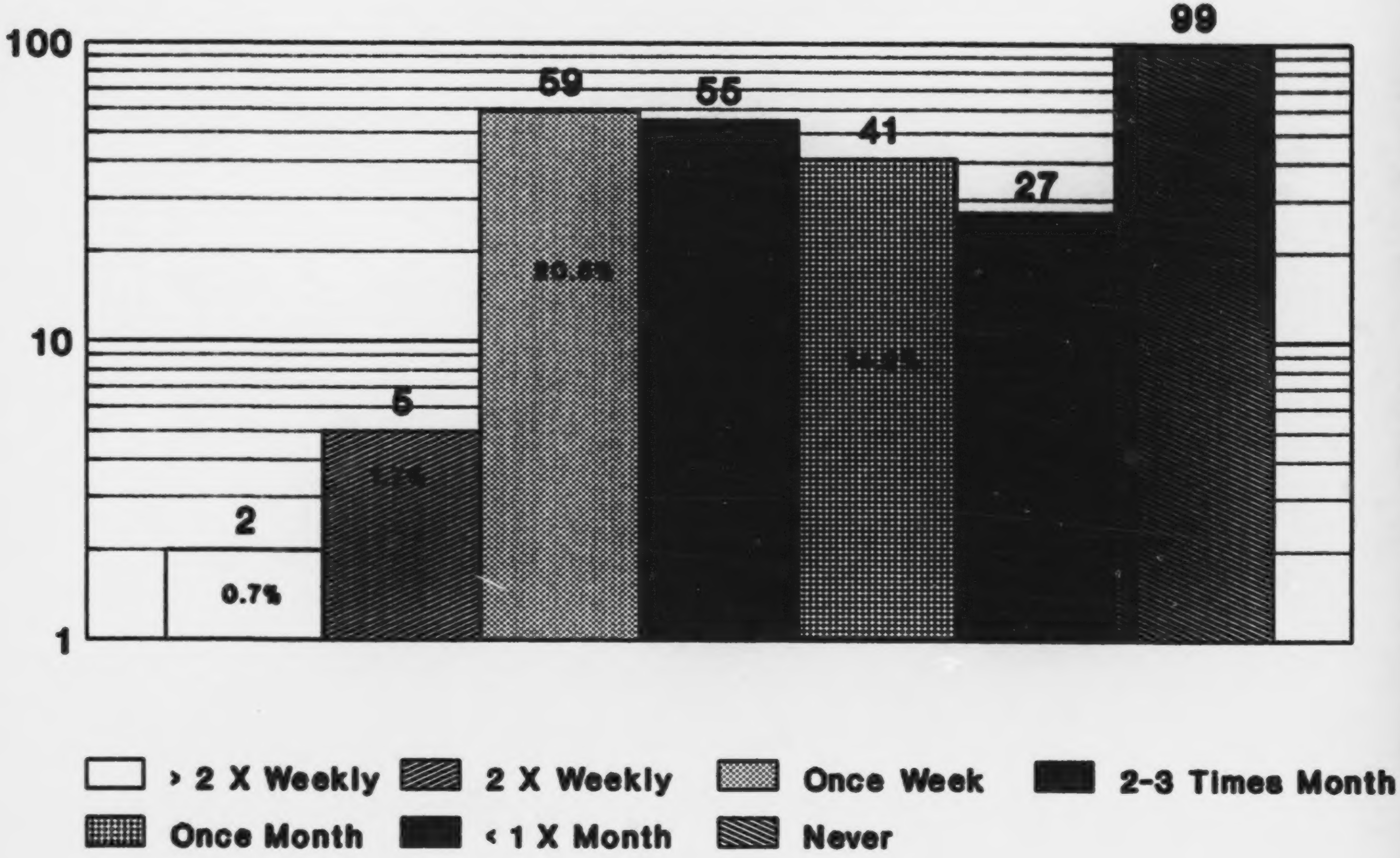
n=287

Figure 24
Go To The Bar/Taverns



n=290

Figure 25
Go To The Bank



n=288

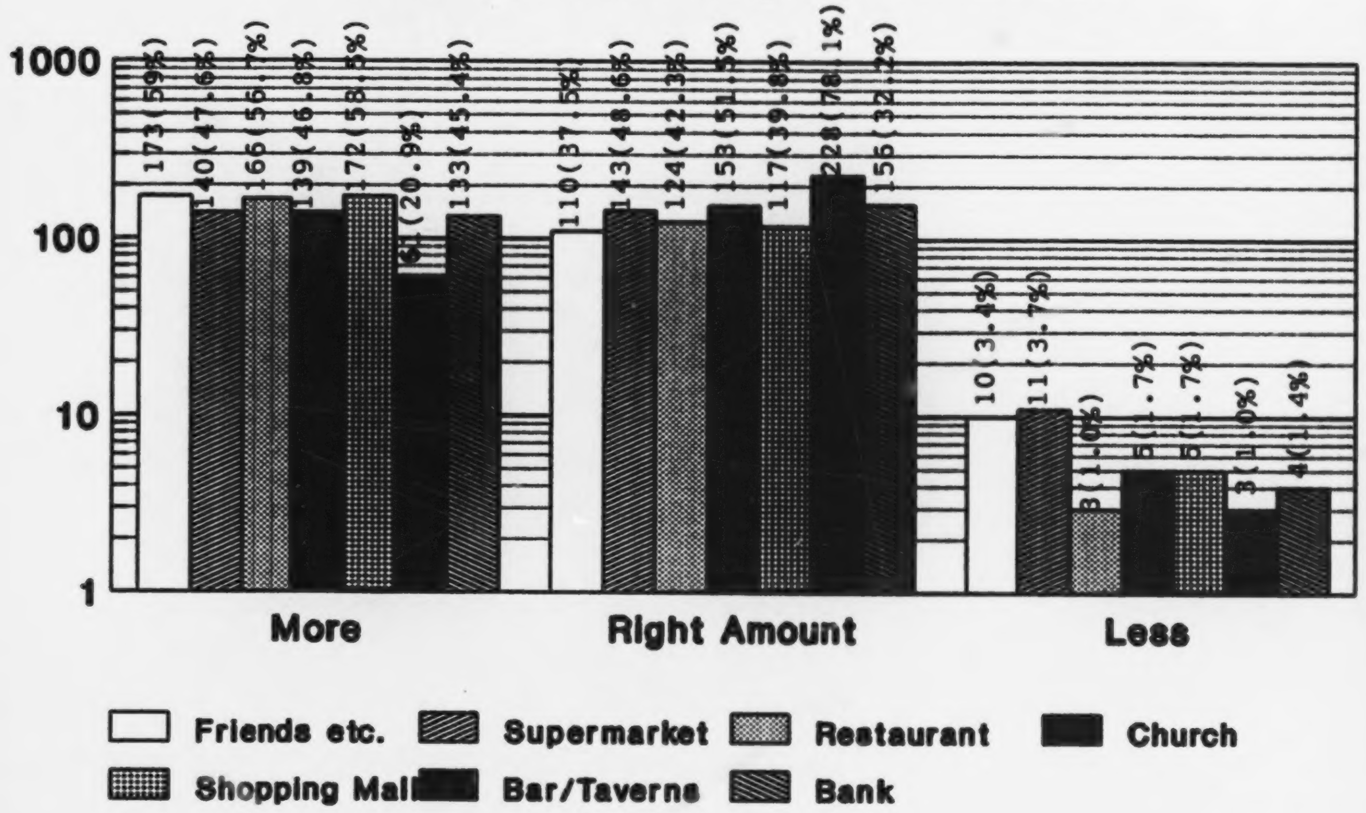
More than 50% indicate that they are satisfied with the frequency with which they go to church, bars and banks. Between 30% to 49.9% are satisfied with the frequency they visit friends/relatives/neighbors, supermarkets, restaurants and shopping centers. Very few indicated that they would like to perform the activities less. The majority would like to perform them more. More than 50% would like to visit with their friends/family/neighbors, and go to restaurants and shopping centers more. Between 30% to 49.9% wanted to visit supermarkets, churches and banks more. Less than 30% want to visit bars more. The exact figures are presented in Table 12 and Figure 26.

Table 12

Satisfaction with Frequency

Activity	More Often	Right Amount	Less Often
Visit with friends/ relatives/ neighbors	173(57.7%)	110(36.7%)	10(33.3%)
Visit supermarket	140(46.7%)	143(47.7%)	11(3.7%)
Go to restaurants	166(55.3%)	124(41.3%)	3(1.0%)
Go to church	139(46.3%)	153(51.0%)	5(1.7%)
Go to shopping center	172(57.3%)	117(39.0%)	5(1.7%)
Go to bars	61(20.3%)	228(76.0%)	3(1.0%)
Go to bank	133(44.3%)	156(52.0%)	4(1.3%)

Figure 26
Like To Do Activities
(More, Just Right, or Less)



The next series of questions involved typical leisure activities. Respondents were asked to quantify the number of times they had participated in these activities in the past 12 months. Going to movies was the one activity that a sizable number of respondents (68 or 22.7%) had been to six times or more in the past 12 months. Sports events came in second with 46 (15.3%). The rest of the activities, going to theatre and music performances, athletic clubs and community/civic group meetings had less than 10% going six times or more.

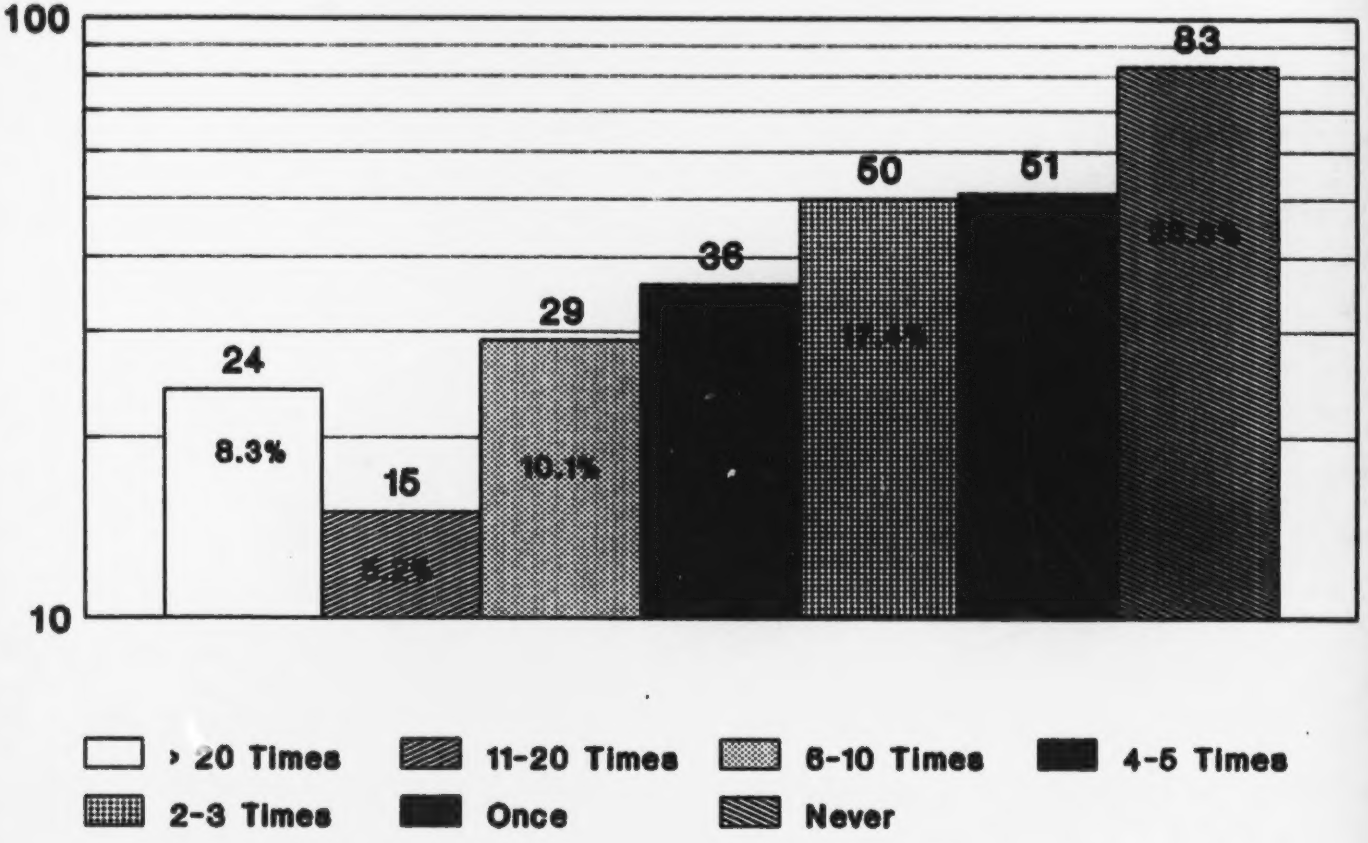
A disturbingly large percentage of respondents have not been to any of these activities in the past 12 months. More than 50% have never been to a theatre performance, a music performance, athletic clubs/facilities and community/civic group meetings. More than 40% have never been to a sports event, and more than 20% have never been to a movie. Results are summarized in Table 13. Figures 27 to 32 give a graphical presentation of the precise figures.

Table 13

Frequency of Participation in Leisure Activities

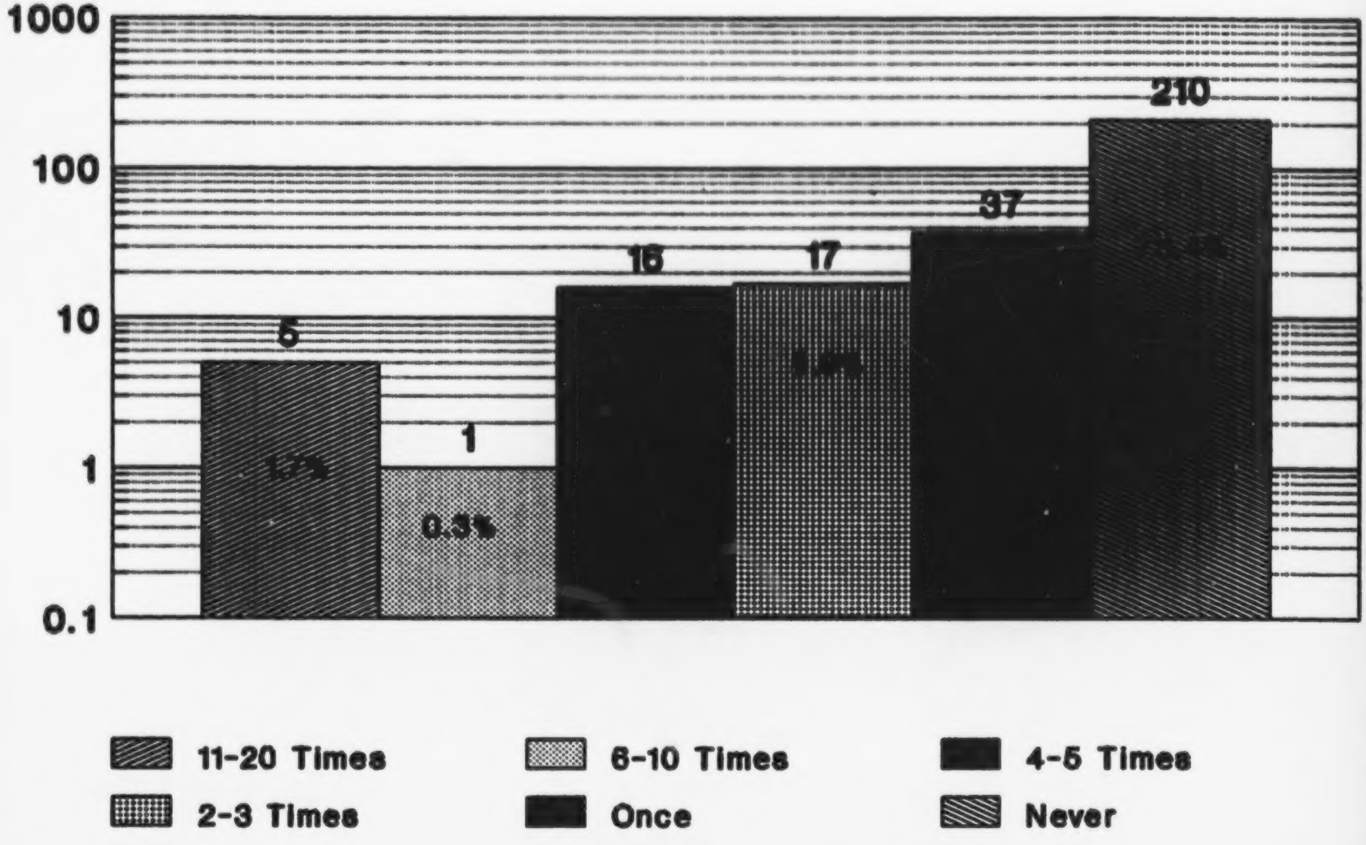
Activity	Frequency 6 times or more	 Less than 6 times	 Never
Go to movies	68(22.7%)	137(45.7%)	83(27.7%)
Go to live theatre performance	6(2.0%)	70(23.3%)	210(70.0%)
Go to live popular music performance	17(5.7%)	101(33.7%)	165(55.0%)
Go to sports event	46(15.3%)	108(36.0%)	137(45.7%)
Athletic Clubs/ Facilities	24(8.0%)	23(7.7%)	241(80.3%)
Community/Civic Groups	13(4.3%)	5(1.7%)	258(86.0%)

Figure 27
Go To The Movies



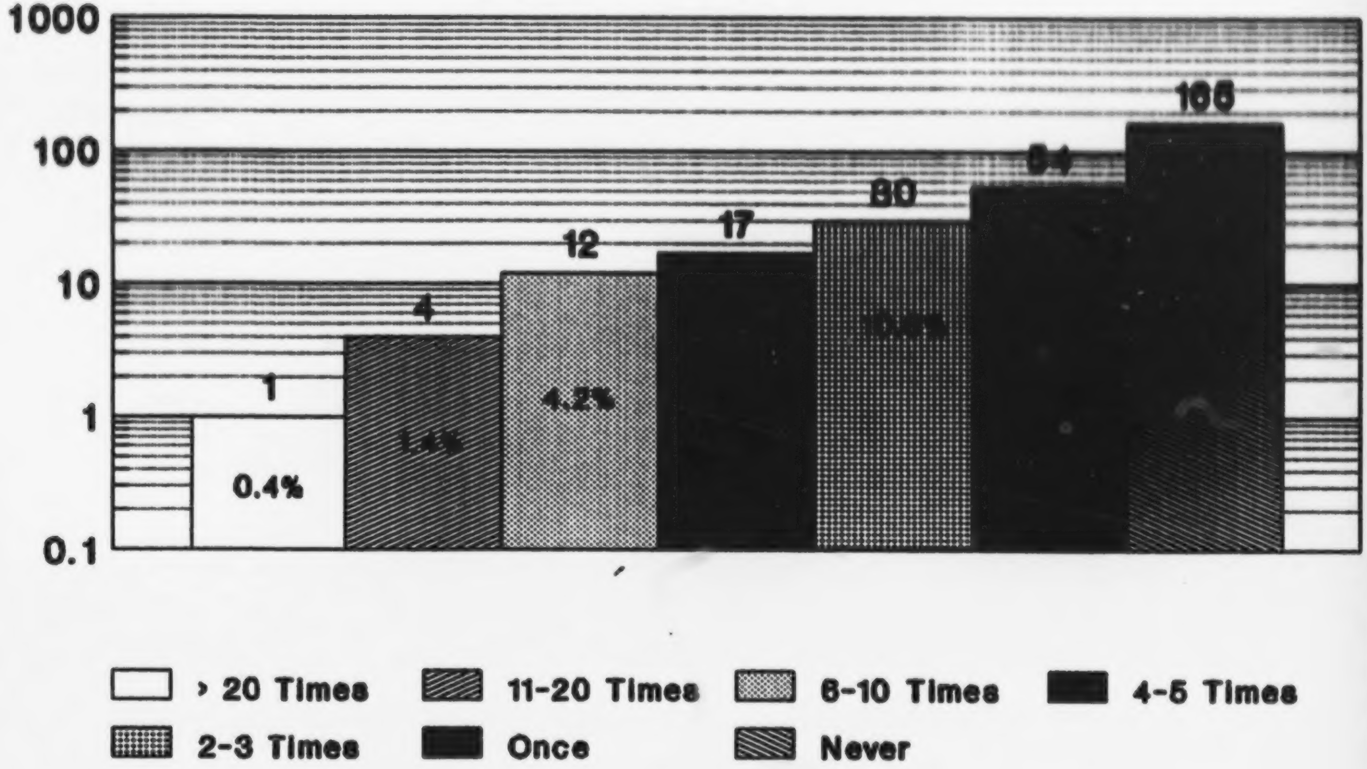
n=288

Figure 28
Go To Live Theater Performance



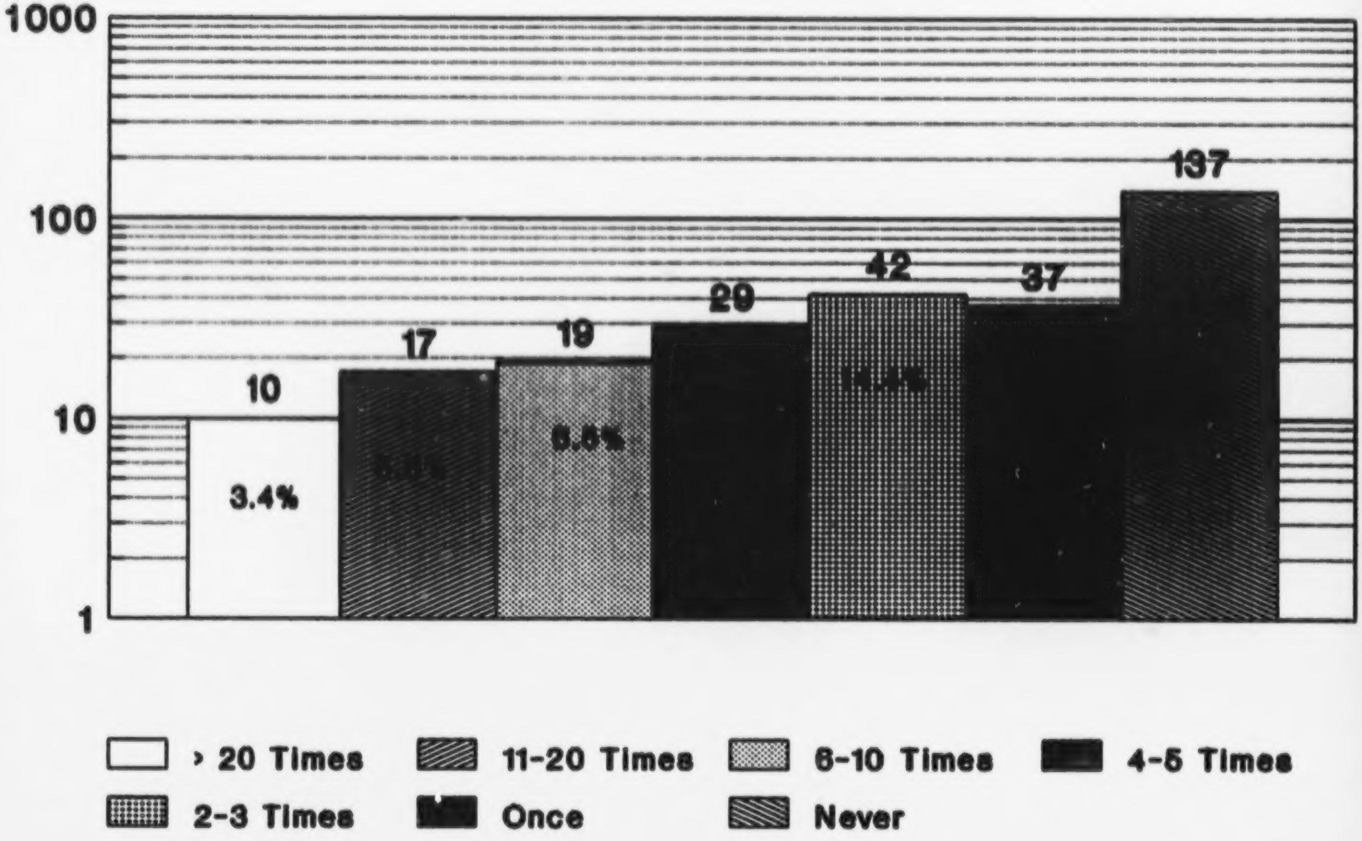
n=286

Figure 29
Go To Live Popular Music Performance



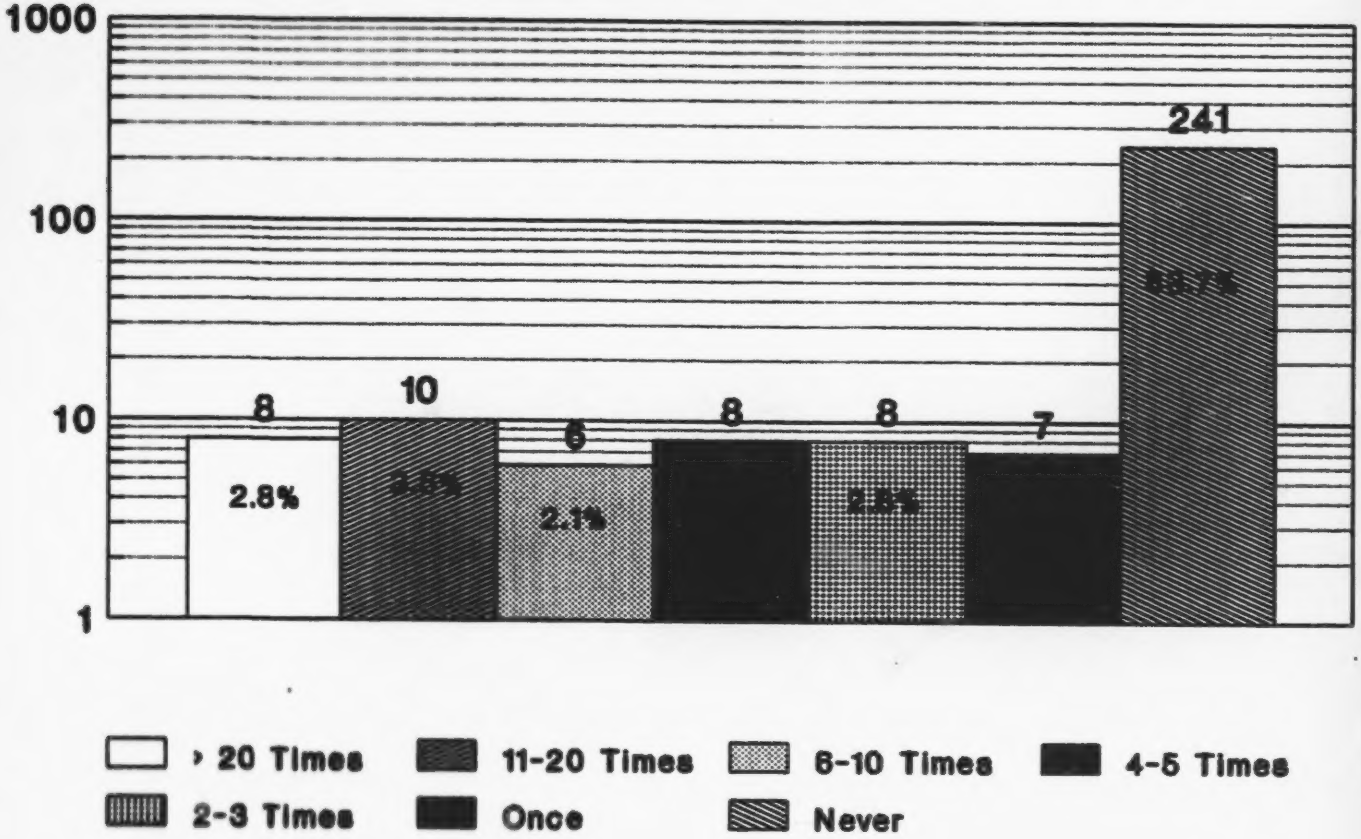
n=283

Figure 30
Go To Sports Events



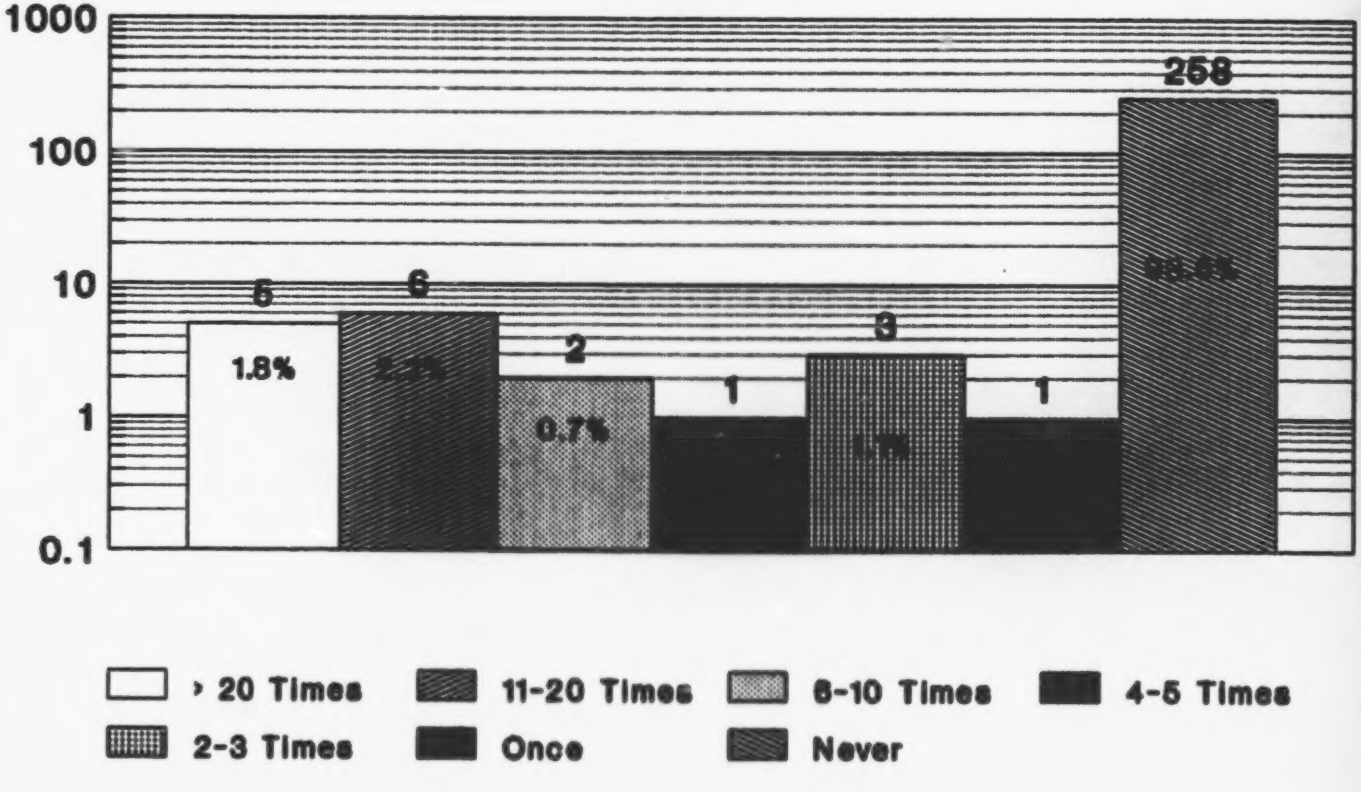
n=291

Figure 31
Go To Athletic Clubs/Facilities



n-288

Figure 32
Go To Community/Civic Group Meetings



n=276

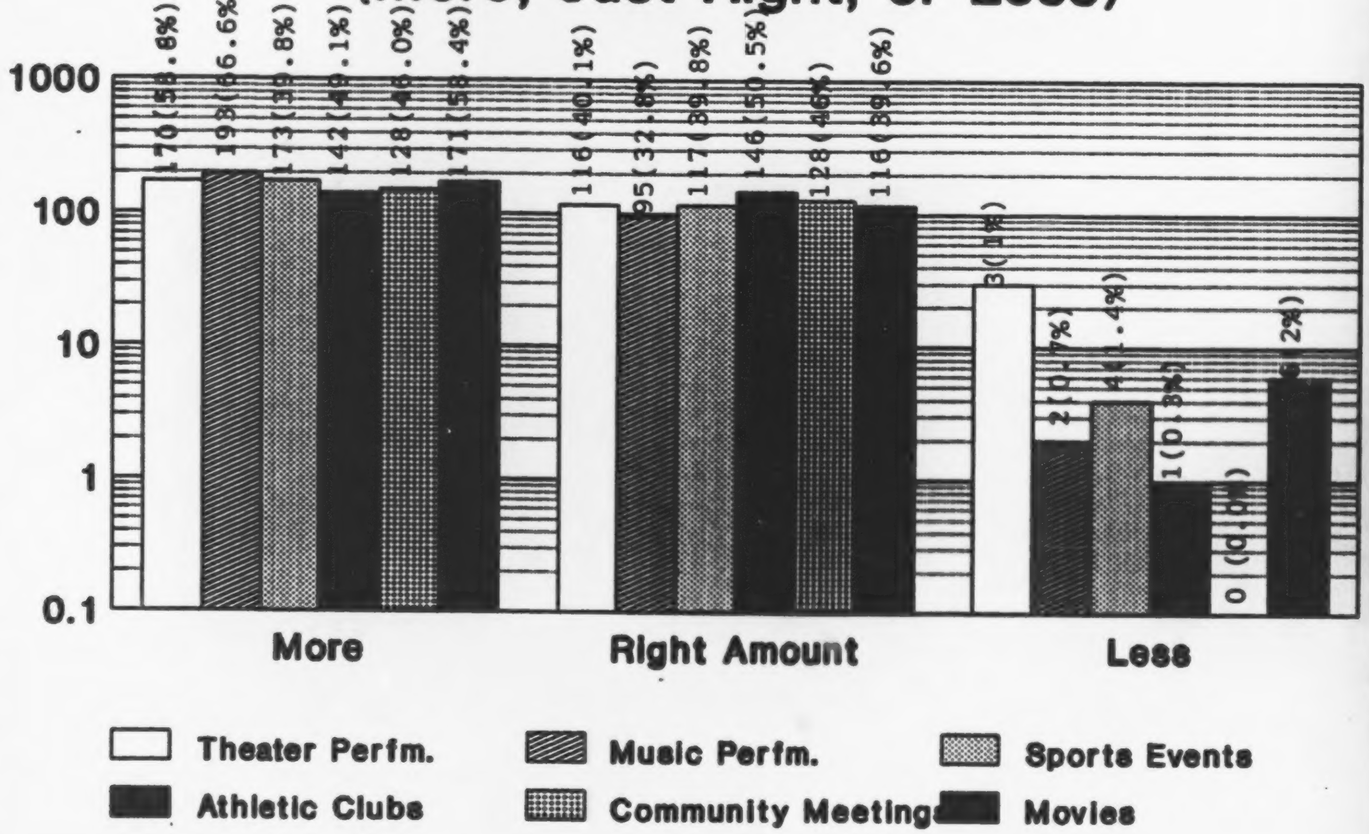
Given the fact that so few are regular participants in these leisure activities, it is suprising that quite a high percentage of respondents are satisfied with the frequency with which they participate in the activities. For each and every activity, more than 30% voiced satisfaction in their current rate of participation. However, most would like to participate more frequently. Going to athletic clubs/facilities was the only activity with less than 50% wanting to participate more. Even there, however, 49.1% would like to increase their rate of participation. As with community activities, very few respondents said they want to perform these activities less. Table 14 summarizes the results from these questions. See also Figure 33.

Table 14

Satisfaction with Frequency

Activity	More Often	Right Amount	Less Often
Go to movies	171(57.0%)	116(38.7%)	6(2.0%)
Go to live theatre performance	170(56.7%)	116(38.7%)	3(1.0%)
Go to live popular music performance	193(64.3%)	95(31.7%)	2(0.7%)
Go to sports event	173(57.7%)	117(39.0%)	4(1.3%)
Athletic Clubs/ Facilities	142(47.3%)	146(48.7%)	1(0.3%)
Community/Civic Groups	150(50.0%)	128(42.7%)	0(0.0%)

Figure 33
Like To Do Activities
(More, Just Right, or Less)



This section in the survey instrument goes on to ask about the residences of the respondents and their surroundings. The majority (111 or 37.0%) reported living in a multi-family home or apartment in a community setting. Following that, 105 (35.0%) said they lived in a single family home in a neighborhood while 49 (16.3%) lived in a single family home in a rural area. Twenty-two (7.3%) were living in an institution, eight (2.7%) in a living facility specifically built or extensively renovated for use as a congregate care facility, and three (1.0%) were staying at a rooming house or residential hotel.

Table 15 illustrates the number of respondents who are living with a certain number of people and the relationships of these people to the respondents.

Table 15

Other Individuals at Same Address

	Number			
Relationship	0	Less than 10	10 or more	100 or more
Family members/ Relatives	142(47.3%)	110(36.7%)	1(0.3%)	0(0.0%)
Personal care Attendant	235(78.3%)	7(2.3%)	1(0.3%)	0(0.0%)
Paid Staff who live there always	206(68.7%)	41(13.7%)	1(0.3%)	0(0.0%)
Paid staff who are there sometimes	161(53.7%)	99(33.02%)	0(0.0%)	0(0.0%)
Other individuals with disabilities	133(44.3%)	93(31.0%)	33(11.0%)	7(2.3%)
Other indiviuals without disabilities	233(77.7%)	10(3.8%)	1(0.3%)	0(0.0%)

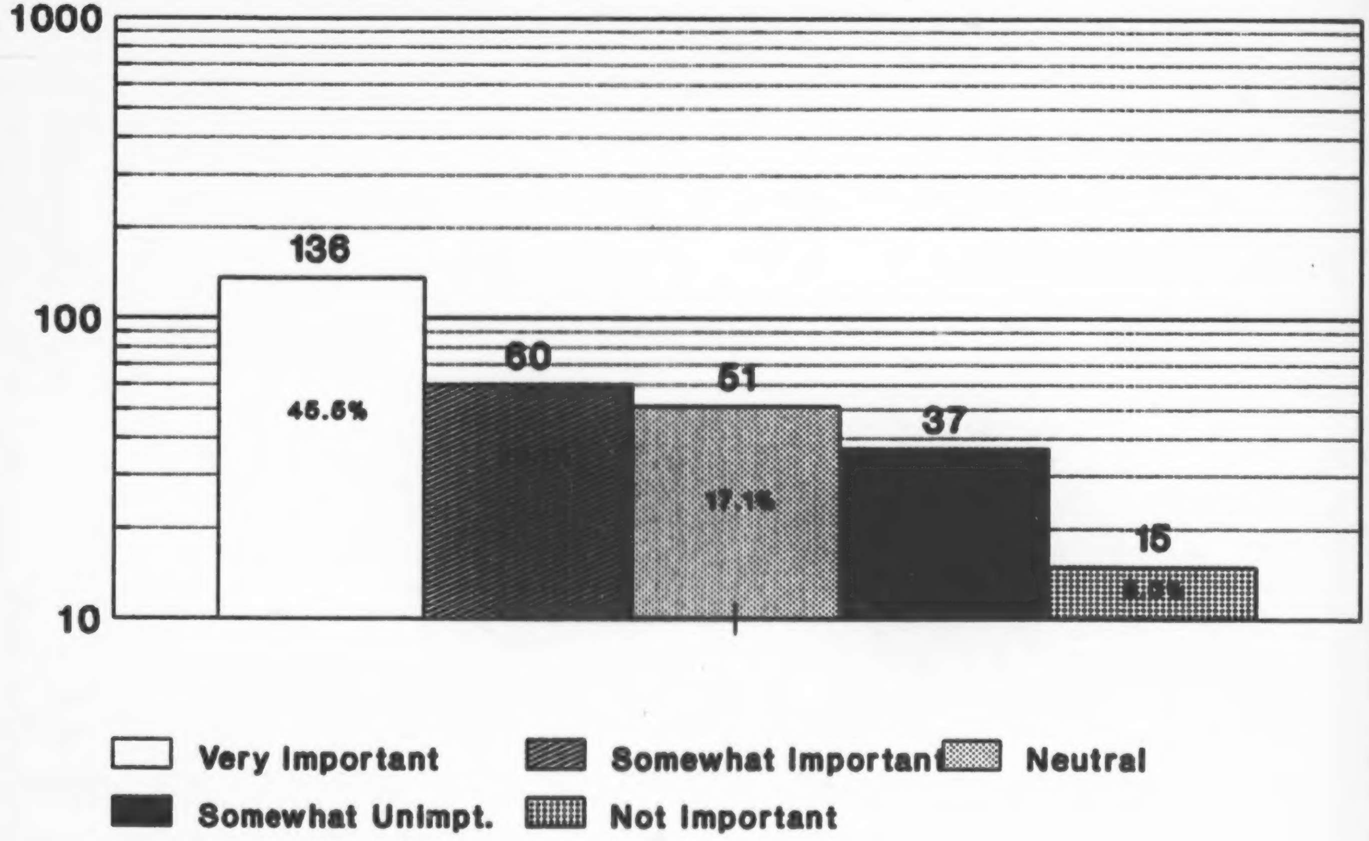
The majority of the respondents (122 or 40.7%) said that they had very good neighbors. Only 19 (6.3%) complained that they did not have good neighbors. The respondents knew an average of two of their neighbors by name, and they visited with only an average of one neighbor. When asked if they ever had felt lonely in the past few weeks, a large majority (180 or 60.0%) responded yes. About 112 (37.3%) said no.

Most of the respondents (185 or 61.7%) said they had friends who are not disabled. A total of 113 (37.7%) said they had no non-disabled friends. However, most (196 or 65.3%) said that the majority of their friends were people with disabilities. Only 98 (32.7%) said most of their friends were nondisabled individuals.

Integration and its Importance

A very small number of respondents (29 or 9.7%) considered themselves to be totally integrated into the community. Twenty-three (7.7%) felt that they were not integrated at all. Most (247 or 82.3%) said they were only somewhat integrated. The majority (136 or 45.3%) considered it very important to be integrated. Fifteen (5.0%) thought it was not important at all, while 148 (49.3%) felt that it was somewhat important.

Figure 34
Importance Of Integration



n=299

CHAPTER 6

Productivity

The section on productivity asked respondents about their jobs and/or any other kind of productive activity they engaged in. At the time of the survey, 111 (37.0%) were working full-time. The majority (150 or 50.0%) were working part-time. Fifteen (5.0%) were looking for work, eight (2.7%) were retired, five (1.7%) were studying or in training and the rest were not working for various other reasons. The majority (290 or 96.7%) have worked for pay at one time or another. Only six (2.0%) have never worked for pay.

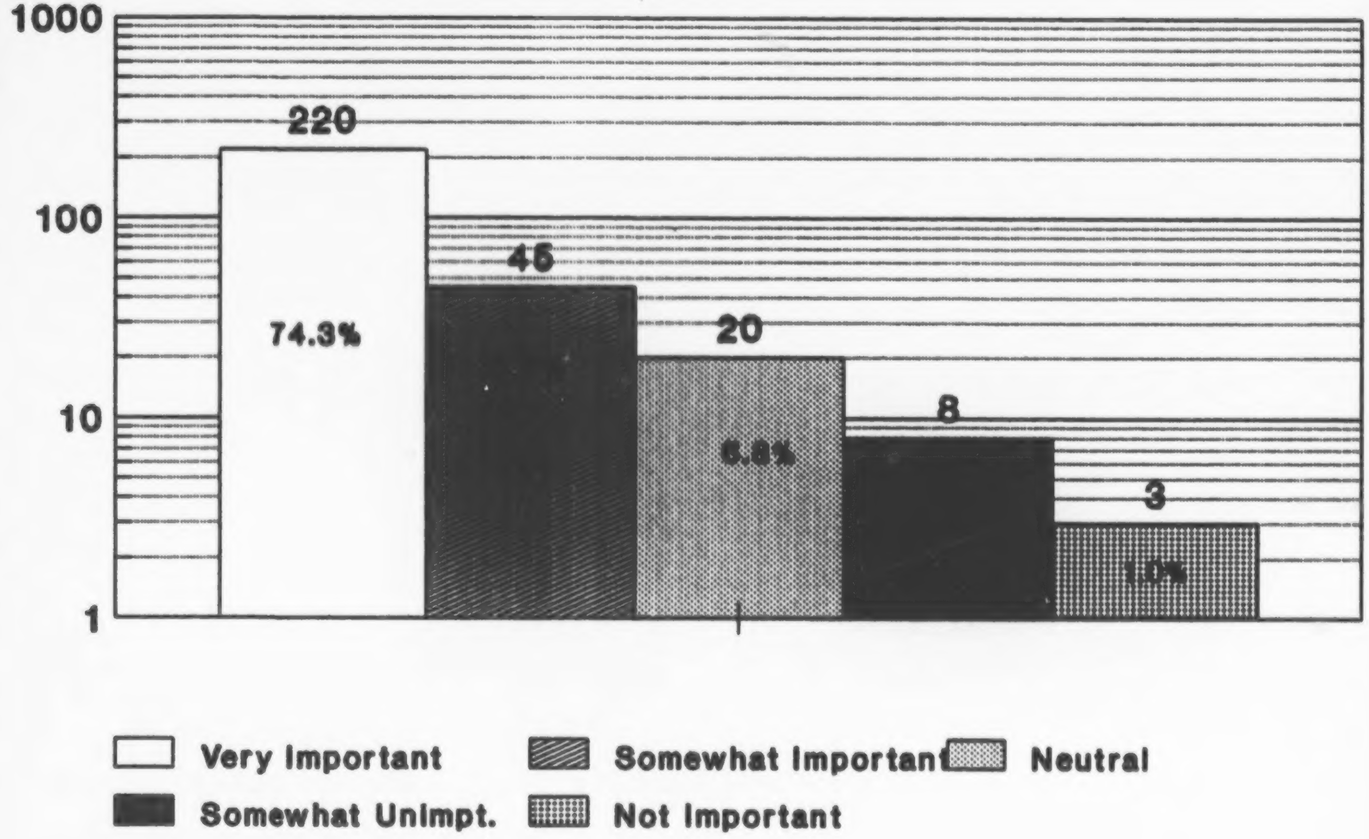
The respondents worked an average of 28 hours a week and earned an average of $68 a week. The average length of time they had their jobs is 4.4 years.

The respondents spend an average of four hours (s = 7.3) doing civic and community work, and two hours (s = 7.0) helping family, friends or neighbors.

Productivity and its Importance

Only 87 (29.0%) respondents thought they were very productive, and 4 (1.3%) said they were not productive at all. The majority (206 or 68.7%) rated themselves as somewhat productive. Two hundred and twenty respondents (73.3%) claimed that being productive is very important to them. Only 11 (3.7%) did not think it was important. Forty-five (15.0%) thought it was somewhat important while 20 (6.7%) felt neutral about it (see Figure 35).

Figure 35
Importance Of Productivity



n=296

CHAPTER 7

Supports/Services/Assistance Needed

This section contained a variety of services that are essentially similar to those in Section C (discussed in Chapter 3). Respondents were asked to indicate their level of need for each service. If they were not receiving a service they said they needed, they were asked to indicate the reason why they were not receiving it. In general, there was a 20% to 30% non-response rate on most of the questions concerning their level of need.

The results revealed that transportation services ranked highest among all services for which a strong need is indicated. Others included individual support services, medical services and recreational/leisure services. Because of the age range of the respondents, it is not surprising that educational services are seldom quoted. Fourteen specific services had a minimum of 20% of the respondents indicating a strong need for them. These services, ranked in descending order from the most frequently to the least frequently cited were:

1. Transportation to and from non-daily activities
2. Transportation to and from work/school/ day activity
3. Transportation for leisure time weekdays
4. Transportation for leisure time weekends
5. Income Assistance
6. Recreation/leisure services

7. Food assistance/food stamps
8. General medical services
9. Dental services
10. Payment for or provision of medication
11. Transportation training
12. Case management
13. Companion/friend advocate program
14. Health insurance (private)

Tables 16 - 23 present more detailed figures of the level of need for each group of services. Services are omitted where less than 10% of the respondents indicated a need for them.

Table 16

Case Coordination Service

Service	Some Need	Strong Need
Case Management	40(13.3%)	67(22.3%)

Table 17

Residential Support Services

Service	Some Need	Strong Need
Housing Subsidy	14(4.7%)	33(11.0%)

Table 18

Educational Supports/Services

Service	Some Need	Strong Need
Adult Literacy/ Basic Education	14(4.7%)	49(16.3%)
Vocational/Technical or Vocational Education	25(8.3%)	54(18.0%)

Table 19

Employment/Vocational/Day Supports/Services

Service	Some Need	Strong Need
Employment Service	12(4.0%)	30(10.0%)
Vocational Training Services	19(6.3%)	33(11.0%)

Table 20

Health Supports/Services

Service	Some Need	Strong Need
General Medical Services	89(29.7%)	74(24.7%)
Dental Services	74(24.7%)	71(23.7%)
Health Insurance (private)	43(14.3%)	59(19.7%)
Payment for or Provision of Medication	36(12.0%)	72(24.0%)

Table 21

Individual Support Services

Service	Some Need	Strong Need
Mental Health/ Counselling Services	24(8.0%)	30(10.0%)
Income Assistance	42(14.0%)	105(33.0%)
Food Assistance/ Food Stamps	40(13.3%)	78(26.0%)
Companion/Friend Advocate Program	31(10.3%)	63(21.0%)
Self Help/Support Groups	32(10.7%)	46(15.3%)
Community Support Services	20(6.7%)	34(11.3%)

Table 22

Transportation Services

Service	Some Need	Strong Need
Transportation to and from work/school/ day activity	28(9.3%)	132(44.0%)
Transportation to and from non-daily activity	33(11.0%)	136(45.3%)
Transportation for leisure time (weekdays)	37(12.3%)	131(43.7%)
Transportation for leisure time (weekends)	34(11.3%)	129(43.0%)
Transportation Training	24(8.0%)	68(22.7%)

Table 23

Recreation/Leisure Services

Service	Some Need	Strong Need
Recreation/Leisure Service	83(27.7%)	87(29.0%)

Respondents were generally unable to provide a reason for not receiving a service they indicated a need for. The non-response rate was as high as 90% in some instances. The average non-response rate was between 50% to 60%. For most services, the most frequently quoted reasons for not receiving them were non-eligibility by type or degree of disability, income/means, non-availability in the area, having no knowledge of the existence of the service, and limited availability of the service. Where health services are concerned, the additional reason given was that the service is too expensive to obtain.

Chapter 8

Summary and Recommendations

In examining the voluminous amount of data produced by this survey, some important factors must be noted. The Services Received and Satisfaction Section yielded a high degree of satisfaction. The level of satisfaction was relatively high for the majority of people who were interviewed and these persons were satisfied with the programs. However, there are many studies which have concluded that mentally retarded individuals (74% of this sample) are satisfied with relatively little, so that when dissatisfaction is expressed, something has to be very wrong.

In four of the services there was a strong dissatisfaction response of above 20%. These four programs/ services are institutional care, transportation for leisure time during weekdays, transportation for leisure time during weekends, and recreational/leisure services. When a person is not satisfied with a service which is provided by the government, the causes may be many.

The major reason given for dissatisfaction with institutional care was that the service is not suited to individual situations. In the case of transportation services, the two major reasons given were that they were not receiving enough transportation services and that the services were not suited to individual needs. The former reason is the one major reason for dissatisfaction in recreation/leisure services. This indicated that existing institutional care and transportation services ought to be evaluated and that transportation and recreation/leisure services should be expanded.

Independence is the ability to choose what happens to you in your daily life. The fundamentals of independence are guaranteed in the United States. According to P.L. 100-146, independence is "the extent to which persons with developmental disabilities exert control and choice over their own lives." Most respondents, whether they are adults who should be making as many choices for themselves as possible or whether they are children (up to 22 years) who should be learning to make choices for themselves, said they wanted to be independent. Independence was highly valued among people with developmental disabilities. Although the overwhelming majority (74.7%) considered independence of extreme importance, only 15.7% thought themselves very independent. Only in isolated areas (like decorating their rooms, choosing what to do in the evenings, and deciding what to do with their spending money) did a significantly high percentage of the respondents said they can choose to do what they wanted.

As may be seen from the facts presented, the amount of independence that people with developmental disabilities have in their lives varies considerably. However, it does appear that respondents do not have the degree of independence that they would like. When respondents did not choose, their families usually did.

Community integration for people with developmental disabilities may be defined as four crucial points:

1. the chance to participate in all the activities in the community open to citizens who are not disabled;
2. the chance to have friends who are not disabled;
3. the opportunity to live in homes similar to those of citizens who are not disabled; and
4. the opportunity to use the same community resources which are available to citizens who are not disabled.

In terms of integration, very high percentages report never participating in leisure activities that non-disabled individuals participate in. A majority of the respondents (65.3%) said most of their friends were disabled individuals. While 45% considered it very important to be integrated, only 9.7% said they were totally integrated into the community. It is obvious that much has yet to be done to integrate the disabled individuals of Mississippi into the larger community.

Work can provide the opportunity for integration; it can be the place to interact with people who are not disabled as well as meeting new friends. To work for pay also is tied to independence; a job at a decent wage allows a person to choose for him/herself how and where to live.

According to P.L. 100-146, productivity means "engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or engagement by a person with developmental disabilities in work which contributes to a household or community."

As for productivity, 28 hours at $68 a week was indicated by the average respondent, figures that are vastly different from those in the general population. These figures become even more variant when only the mentally retarded respondents are considered. These individuals worked an average of 25 hours a week and are paid an average of $26.50 a week. Thus, while 73.7% of the respondents thought it very important to be productive, only 29.0% thought they actually were very productive. Lack of productivity in turn makes it difficult for these individuals to attain the independence they want.

An important aspect of this survey was to discover the services needed by developmentally disabled individuals. Section 6 of the survey revealed that transportation services topped the list of needs, followed by income and food assistance, recreation/leisure services, health services, case management, and companion/friend - advocate programs.

The data in this study supports the premise that although people with developmental disabilities have special needs, their basic needs are the same as all members of society. People with developmental disabilities, like all people need to work and contribute to society.

The persons we interviewed with developmental disabilities desire the fundamental right to live, work and spend enjoyable time in leisure activities. They want the choices of how, where and with whom they want to live.

From our interviews, we conclude that persons with developmental disabilities have the same wants, desires, aspirations, dreams, feelings, and rights as do persons without disabilities, and want the same opportunities throughout their lives for happiness and personal achievement as do persons without disabilities.

Finally, the persons we interviewed can very well express their preferences, needs, wants, and desires. Therefore, ongoing consumer satisfaction studies should be conducted in such a way as to demonstrate consumer input and outcomes related to the consumers' quality of life and happiness.

APPENDIX A:

SURVEY INSTRUMENT

A. ELIGIBILITY/SCREENING

These items will generally be asked over the telephone with the individual or someone (such as a parent or guardian) who can set up a personal interview with the the individual. If the screening is successful, arrange for a personal interview.

1. How old are you (the individual)?

__ __

2. Did your (the individual's) disability begin before the age of 22?

○
1 = Yes
2 = No
3 = Don't Know

(If the answer is 2 or 3, terminate the screening process)

3. What is the primary medical diagnosis or description for your (the individual's) disability?

__ __

1 = None
2 = Autism
3 = Blindness/severe visual impairment
4 = Cerebral palsy
5 = Cystic fibrosis
6 = Deafness/severe hearing impairment
7 = Emotional (including chronic mental illness)
8 = Epilepsy/seizure disorder
9 = Head injury
10 = Mental retardation
11 = Multiple sclerosis
12 = Muscular dystrophy
13 = Orthopedic impairment
14 = Speech/language impairment
15 = Spina bifida
16 = Spinal cord injury
17 = Deafness and Blindness
18 = Other neurological impairment
19 = Other(s), such as learning disability, developmental delay, etc. please specify: ____________________
____

(If the answer is none, terminate the screening process)

4. What other disabilities do you (the individual) also experience? Circle all that apply.

1 = None
2 = Autism
3 = Blindness/severe visual impairment
4 = Cerebral palsy
5 = Cystic fibrosis
6 = Deafness/severe hearing impairment
7 = Emotional (including chronic mental illness)
8 = Epilepsy/seizure disorder
9 = Head injury
10 = Mental retardation
11 = Multiple sclerosis
12 = Muscular dystrophy
13 = Orthopedic impairment
14 = Speech/language impairment
15 = Spina bifida
16 = Spinal cord injury
17 = Deafness and Blindness
18 = Other neurological impairment
19 = Other health conditions, such as cardiac, gastrointestinal, etc., please specify: ________________
20 = Other(s), please specify: ________________
____

21 = Behavior problems

These functional screening items are subjective, but must be based on reality. The surveyor should ask both the consumer and the surrogate, if necessary, and then make judgments. In asking the questions below about children under the age of 18, the level of assistance needs to be judged on the basis of children without disabilities (i.e., "an unusual amount of assistance"). If the needs of the child are the same as those for a child without disabilities, the responses should be "none," in terms of the amount of assistance needed.

5. How much assistance or help do you (the individual) need in self care (e.g., bathing, grooming, eating)?

0 = None
1 = A little
2 = A lot (Substantial)

6. How much assistance or help do you (the individual) need from people or assistive devices in communicating to and understanding others?

0 = None
1 = A little
2 = A lot (Substantial)

7. How much assistance or help do you (the individual) need in acquiring new skills or behaviors (learning new things)?

○
0 = None
1 = A little
2 = A lot (Substantial)

8. How much assistance or help from people or assistive devices (e.g., wheelchair) do you (the individual) need in moving from place to place? (NOTE: This question refers to personal mobility, not need for transportation.)

○
0 = None
1 = A little
2 = A lot (Substantial)

9. How much assistance or help do you (the individual) need in managing your (the individual's) life, making decisions, and protecting your (the individual's) own interests?

○
0 = None
1 = A little
2 = A lot (Substantial)

(The following two questions, 10 and 11, should be reserved for individuals age 18 and older.)

10. How much assistance or help do you (the individual) or would you (the individual) need in order to live on your (their) own?

○
0 = None
1 = A little
2 = A lot (Substantial)
9 = NA (child)

11. How much assistance or help do you (the individual) need to maintain a source of income (generally through employment) sufficient to support yourself (the individual)?

○
0 = None
1 = A little
2 = A lot (Substantial)
9 = NA (child)

Adults: If an adult does not score "2"s on at least three of the items 5 through 11, terminate the screening.

Children under 18: If the child does not score "2"s on at least two of the items 5 through 9, terminate the screening.

The surveyor should review the answers to the screening when s/he is on site.

B. DEMOGRAPHICS

For each of the questions, enter the most appropriate response either in the box to the left of the question, or in the spaces provided. It is not necessary to enter lead zeroes (e.g., if date of birth is June 1, 1959 it may be entered as 06/01/59 or 6/1/59.)

1. If a surrogate is assisting with responses to this survey, what is the surrogate's relationship to the individual?

○

1 = Parent/Spouse/Other Relative
2 = Other Surrogate (substitute or foster family member)
3 = Service Provider
4 = Friend or Advocate
5 = Other (please specify) ______________________
9 = NA (no surrogate is assisting the individual)

2. In what state, town and zip code do you (the individual) live?

____

Town/City State Zip Code

3. What is your (the individual's) exact date of birth?

___ ___/___ ___/___ ___
month day year

4. What is your (the individual's) marital status?

○

1 = Never married
2 = Married
3 = Separated or divorced
4 = Widowed

5. What is your (the individual's) gender?

○

1 = Male
2 = Female

6. Approximately how many years did you (the individual) spend in each of the following educational settings? (States may wish to enter the names of their specific educational options here.) The purpose of this question is to find out the total number of years the individual spent in school.

Early Intervention ___ ___
Preschool ___ ___
Elementary School ___ ___
Junior High/Middle School ___ ___
High School ___ ___
Trade or Vocational School ___ ___
College ___ ___
Graduate or Professional ___ ___
Homebound Education ___ ___
Special School or Program with no grades ___ ___
Type of setting unknown (enter number of years) ___ ___

7. What was the last year you (the individual) attended school?

___ ___ ___ ___

8. Was most of the education received in:

1. Special School (Residential-during academic year only)
2. Special School (Day)
3. Special Class in a Regular School
4. Resource Room in a Regular School
5. Regular Class in a Regular School
6. Homebound Education
7. Special Residential School Out of State
8. Residential Facility for Persons with Disabilities
9. Residential Facility for Persons with Mental Illness, Challenging Behavior
0. Not Applicable (i.e., person received no formal education)

9. Which of the following best describes your (the individual's) race?

___ ___

1. White
2. Black or Negro
3. Hispanic
4. Japanese
5. Chinese
6. Filipino
7. Korean
8. Vietnamese
9. (Amer) Indian
10. Asian Indian
11. Hawaiian
12. Guamanian
13. Samoan
14. Eskimo
15. Aleut
16. Other (Specify):

______________________ ________________
(print tribe):

10. How many times have you (the individual) changed addresses in the past five years (enter actual number)?

___ ___

11. Who would best be called a "primary caregiver" for you (the individual)? Circle one.

○

1 = You (The Individual)
2 = Parent/Spouse/Other Relative
3 = Foster Family Member
4 = Legal Guardian
5 = Friend or Advocate
6 = Paid Personal Care Attendant
7 = Service Provider
8 = Other (please specify) ______________________

12. Are you (the individual) a member of a consumer/advocacy group such as the Association for Retarded Citizens, The National Head Injury Foundation, The National Alliance for the Mentally Ill, United Cerebral Palsy, The Epilepsy Foundation of America, People First, or any other groups?

○

1 = Yes (Specify)______________________________
0 = No

13. Is anyone in your (the individual's) home a member of a consumer/advocacy group?

○

1 = Yes (Specify)______________________________
0 = No
9 = Don't Know or Individual Lives Alone

14. Is anyone in your immediate family a member of a consumer/advocacy group?

○

1 = Yes (Specify)______________________________
0 = No
9 = Don't Know or No Family

C. SERVICES AND SATISFACTION

Surveyors may introduce this section in this way: The next few questions are about your (the individual's) feelings. We want to hear about where you (the individual) live, what you (the individual) do, and what services you (the individual) are currently receiving.

1. Are you (the individual) satisfied living here, or would you like to live someplace else?

○

1. Stay here
2. Stay here but with changes, e.g., different roommates, different staff, more privacy
3. Move to a different place (geographically)
4. Move to a different place (Type of setting)
8. No opinion
9. Don't know or no answer

2. If you (the individual) are working (work includes day programs, sheltered workshops, etc.): Please tell me how true this is about your (the individual's) job. Getting to and from work is convenient. Is this very true, somewhat true, neither true nor untrue, not very true or not true at all? If the person is not working skip to question #4.

○

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion
9. Not applicable

3. All things considered, how satisfied are you (the individual) with your job?

○

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion
9. Not applicable

4. If you (the individual) are in school: Please tell me how true this is about school. Getting to and from school is convenient. How true is this?

○

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion
9. Not applicable

5. All things considered, how satisfied are you (the individual) with school?

○

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion
9. Not applicable

6. If the individual is not working or in school: Please tell me how true this is about getting around the place where you (the individual) live and going from place to place. Getting around is convenient. How true is this?

○

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion
9. Not applicable

For the next two questions, surveyors may use the word "happy" as a prompt for ascertaining level of satisfaction. If surrogates are responding, they should be responding to their perceptions of the level of satisfaction of the individual with a disability. If it is absolutely impossible to measure or assess level of satisfaction, these three items may be left blank.

7. How satisfied are you (the individual) with life in general?

○

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion

8. Overall, how satisfied are you (the individual) with the ways you spend your spare time?

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
8. No opinion

9. Getting around in my (the individual's) spare time is convenient. How true is this statement?

1. Very true
2. Somewhat true
3. Neither true nor untrue
4. Not very true
5. Not true at all
8. No opinion

10. What has been your (the individual's) experience with the following programs or agencies? State specific names may be added under specific Federal program names.

1 = No experience
2 = Application is pending
3 = Application was denied
4 = Received and was satisfied
5 = Received and was dissatisfied
9 = Don't know

a. Aid to Families with Dependent Children (AFDC) ___

____

b. Vocational Rehabilitation ___

____

c. Education (Regular or Special) ___

____

d. Medical Assistance (Medicaid/MA) ___

____

e. Mental Retardation/Developmental Disabilities (State Programs) ___

____

f. Independent Living Centers (CIL) ___

____

g. Supplemental Security Income (SSI) ___

____

1 = No experience
2 = Application is pending
3 = Application was denied
4 = Received and was satisfied
5 = Received and was dissatisfied
9 = Don't know

h. Social Security Disability Income (SSDI) ___

____

i. Maternal And Child Health (MCH) ___

____

j. Crippled Children's/Special Health Services ___

____

k. Community Mental Health Services ___

____

l. HUD Section 8 Rent Certificate ___

____

11. Satisfaction With Services the Person is Currently Receiving

Refer to Appendix 1 in the Surveyor's Guide for a description of services.

For services the person is currently receiving, obtain the person's (or the surrogate's) rating of satisfaction with the service on this five point scale:

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

A few services are very short in duration. They are marked with the notation "(recently)". For these services, obtain a satisfaction rating if the service was received within the past year.

ONLY for services that are rated "DISSATISFIED" or "VERY DISSATISFIED," ask for the main reason for the dissatisfaction, and code the reason in these categories:

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

SATISFACTION WITH SERVICES

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

			How Satisfied?	If Dissatisfied, Why?
1.0	CASE COORDINATION SERVICES			
1.1	Assessment/Individual Plan Development (recently)	1.1	___	___
1.2	Case Management	1.2	___	___
1.3	Information and Referral (recently)	1.3	___	___
2.0	RESIDENTIAL SERVICES			
2.1	Institution (50 or fewer people)	2.1	___	___
2.2	Institution (more than 50 people)	2.2	___	___
2.3	Nursing home (50 or fewer people)	2.3	___	___
2.4	Nursing home (more than 50 people)	2.4	___	___
2.5	Group Home or Apartment, 16 or More People	2.5	___	___
2.6	Group Home or Apartment, 10 to 15 People	2.6	___	___
2.7	Group Home or Apartment, 6 to 9 People	2.7	___	___
2.8	Group Home or Apartment, 1 to 5 People	2.8	___	___
2.9	Supervised Home or Apartment	2.9	___	___
2.10	Room and Board Domiciliary Care	2.10	___	___
2.11	Family Care (Substitute or Foster Family) (Only one of the above, 2.1-2.11 can be checked)	2.11	___	___
2.12	Homemaking Assistance or Training	2.12	___	___
2.13	Housing Subsidy (e.g., Section 8)	2.13	___	___
2.14	Architectural Modifications	2.14	___	___

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

3.0 EDUCATIONAL SERVICES

			How Satisfied?	If Dissatisfied, Why?
3.1	Early Intervention Services	3.1	____	____
3.2	Preschool Services	3.2	____	____
3.3	Regular Class in a Regular School	3.3	____	____
3.4	Regular Class and Resource Room	3.4	____	____
3.5	Special Class in a Regular School	3.5	____	____
3.6	Special School (Day)	3.6	____	____
3.7	Special School (Residential)	3.7	____	____
3.8	Homebound Education	3.8	____	____
3.9	After School Tutor	3.9	____	____
3.10	Related Services (e.g., aide, attendant)	3.10	____	____
3.11	Summer School/Programs	3.11	____	____
3.12	Adult Literacy/Basic Education	3.12	____	____
3.13	Vocational/Technical or Vocational Education	3.13	____	____
3.14	Post Secondary Education	3.14	____	____

4.0 VOCATIONAL AND OTHER ADULT DAY SERVICES

4.1	Adult Day Service, Non-Developmental	4.1	____	____
4.2	Adult Day Service, Developmental/Habilitative	4.2	____	____
4.3	Partial Hospitalization	4.3	____	____
4.4	Psychosocial Rehabilitation	4.4	____	____
4.5	Day Treatment	4.5	____	____
4.6	Work Activities or Prevocational	4.6	____	____
4.7	Work Adjustment	4.7	____	____
4.8	Sheltered Employment, facility based	4.8	____	____
4.9	Sheltered Employment, non-facility based (e.g., enclaves, mobile work crews)	4.9	____	____
4.10	Supported Employment (Paid, integrated, ongoing support)	4.10	____	____
4.11	Competitive Employment (Time Limited Services)	4.11	____	____
4.12	Job Placement Services	4.12	____	____
4.13	On-site modifications to the work site	4.13	____	____
4.14	On-site aide/attendant	4.14	____	____

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

			How Satisfied?	If Dissatisfied, Why?
5.0	HEALTH SERVICES			
5.1	General/Special Hospitals (recently)	5.1	___	___
5.2	Emergency Health Services (recently)	5.2	___	___
5.3	General Medical Services (recently)	5.3	___	___
5.4	Dental Services (recently)	5.4	___	___
5.5	Health Insurance (private)	5.5	___	___
5.6	Medicaid (Medical Care)	5.6	___	___
5.7	Payment for or Provision of Medical Equipment/Supplies	5.7	___	___
5.8	Payment for or Provision of Medication	5.8	___	___
5.9	Genetic Counseling/Screening (recently)	5.9	___	___
6.0	INDIVIDUAL SUPPORT SERVICES			
6.1	Respite Care, In Home (recently)	6.1	___	___
6.2	Respite Care, Out of Home (recently)	6.2	___	___
6.3	Behavior Management Assistance/Training	6.3	___	___
6.4	Mental Health or Counseling Services (recently)	6.4	___	___
6.5	Protective or Legal Services (recently)	6.5	___	___
6.6	Physical Therapy or Related Services	6.6	___	___
6.7	Occupational Therapy or Services	6.7	___	___
6.8	Communication and Language Services	6.8	___	___
6.9	Attendant Care	6.9	___	___
6.10	Community Living Assistance or Training	6.10	___	___
6.11	Home Health Aides or Visiting Nurse	6.11	___	___
6.12	Adaptive Equipment/Assistive Devices & Training (recently)	6.12	___	___
6.13	Income Assistance (i.e., SSI)	6.13	___	___
6.14	Food Assistance/Food Stamps	6.14	___	___
6.15	Homemaker/Chore Services	6.15	___	___
6.16	Cooking/Meals on Wheels	6.16	___	___
6.17	Companion/Friend-Advocate Program	6.17	___	___
6.18	Self Help/Support Groups	6.18	___	___
6.19	Financial Management Assistance	6.19	___	___
6.20	Community Support Services	6.20	___	___

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

7.0 TRANSPORTATION

			How Satisfied?	If Dissatisfied, Why?
7.1	Transp'n to and from work, school, day activity	7.1	___	___
7.2	Transp'n to and from non-daily services/activities (e.g., medical appointments, shopping)	7.2	___	___
7.3	Transp'n for leisure time (weekdays)	7.3	___	___
7.4	Transp'n for leisure time (weekends)	7.4	___	___
7.5	Vehicle Modification	7.5	___	___
7.6	Transportation Training (driver's education, use of public transportation, etc.)	7.6	___	___

For the items in the CAREGIVER SUPPORT SERVICES section, the caregiver should always be consulted. A caregiver is intended to mean someone other than the consumer. The questions are meant to be asked of a family member or other non-paid person.

8.0 CAREGIVER SUPPORT SERVICES

8.1	Respite Care, In Home (recently)	8.1	___	___
8.2	Respite Care, Outside Home (recently)	8.2	___	___
8.3	Child Day Care	8.3	___	___
8.4	Homemaker/Chore Services	8.4	___	___
8.5	Behavior Management Assistance/Training	8.5	___	___
8.6	Family Counseling (recently)	8.6	___	___
8.7	Parent Training (recently)	8.7	___	___
8.8	Family Education (recently)	8.8	___	___
8.9	Genetic Screening and/or Counseling (recently)	8.9	___	___
8.10	Family Cash Assistance	8.10	___	___
8.11	Family Support Services (Other ____________)	8.11	___	___
8.12	Adult Day Care	8.12	___	___
8.13	Family Support Group	8.13	___	___
8.14	Special Needs Adoption	8.14	___	___

SATISFACTION

1 = VERY SATISFIED
(SERVICE IS VERY GOOD)
2 = SATISFIED
(SERVICE IS GOOD)
3 = IN BETWEEN OR NEUTRAL
(SERVICE IS NEITHER GOOD NOR BAD)
4 = DISSATISFIED
(SERVICE IS BAD)
5 = VERY DISSATISFIED
(SERVICE IS VERY BAD)

REASONS FOR DISSATISFACTION

1 = NOT RECEIVING ENOUGH
2 = POOR QUALITY
3 = TOO EXPENSIVE
4 = NOT SUITED TO INDIVIDUAL NEEDS
5 = DOES NOT HELP
6 = DOES NOT RESPECT PERSONAL DIGNITY
7 = TRANSPORTATION
8 = UNDERSTAFFED
9 = NOT INTEGRATED
0 = ANY OTHER REASON (SPECIFY IN MARGIN)

			How Satisfied?	If Dissatisfied, Why?
9.0	OTHER SERVICES			
9.1	Recreation/Leisure Services	9.1	___	___
9.2	______________________________(Specify)	9.2	___	___
9.3	______________________________(Specify)	9.3	___	___

D. INDEPENDENCE

1. Do you (the individual) own your home or hold the lease for your house or apartment? For children under 16, code 0.

○
1 = Yes
0 = No
9 = Don't Know

2. Did you (the individual) choose the place where you (the individual) live?

○
1 = Yes, the individual chose the place unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown (including court)

3. Did you (the individual) choose your (the individual's) attendant and/or residential support staff?

○
1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

4. Did you (the individual) choose your (the individual's) roommate(s)/housemate(s)?

○
1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

5. Did you (the individual) choose your (the individual's) job (or what you (the individual) do on weekdays)?

○

1 = Yes, the individual chose unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

6. Do you (the individual) usually choose what you (the individual) do on weekends and evenings?

○

1 = Yes, the individual chooses unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

7. Do you (the individual) give your own consent for medical care?

○

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

8. Do you (the individual) determine what clothes you (the individual) wear?

○

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

9. Do you (the individual) usually choose your (the individual's) friends and acquaintances?

○

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

10. Do you (the individual) usually decide how your (the individual's) personal space (home, apartment, bedroom, etc.) is decorated?

○

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

11. Do you (the individual) go to the bank and deposit and withdraw money?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
○ 5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

12. Do you (the individual) pay your own rent, gas/electric, and phone bills?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
○ 5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

13. Do you (the individual) usually decide what things you (the individual) buy with your (the individual's) spending money ?

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
○ 5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

14. Do you (the individual) determine which agencies and organizations provide services and support to you (the individual)?

○

1 = Yes, unassisted
2 = Yes, with assistance from personal unpaid friend
3 = Yes, with assistance from family member
4 = Yes, with assistance from a legal guardian
5 = Yes, with assistance from agency/school staff member
6 = No, personal unpaid friend
7 = No, family member
8 = No, legal guardian
9 = No, agency/school staff member
0 = Other, not applicable, or unknown

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence. A good prompt might be to ask whether the individual makes choices in his/her life.

15. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, independence means "the extent to which persons with developmental disabilities exert control and choice over their own lives." On a scale of 1 to 5, with 1 being totally independent and 5 being totally dependent, how independent do you (the individual) think you are?

1	2	3	4	5
Totally independent				Not at all independent

16. How important is it to you (the individual) to be independent?

○

1. Very important
2. Somewhat important
3. Neutral
4. Somewhat unimportant
5. Not important at all

E. INTEGRATION

1. Did you (the individual) vote in the most recent general election?

○

1 = Yes
0 = No
9 = Not Applicable; consumer under 18 years old

2. About how often do you (the individual) do each of the following:

1 = More than twice a week
2 = Twice a week
3 = Once a week
4 = 2-3 times a month
5 = Once a month
6 = Less than once a month
7 = Never
9 = Not sure or refused

Would you like to do this activity more often, less often, or is this the right amount?

1 = More Often
2 = Right Amount
3 = Less Often

	Frequency	Satis W/ Freq.
a. Visit with close friends, relatives or neighbors	___	___
b. Visit a supermarket or food store	___	___
c. Go to a restaurant	___	___
d. Go to church or synagogue	___	___
e. Go to a shopping center, mall or other retail store to shop	___	___
f. Go to bars, taverns, etc.	___	___
g. Go to the bank	___	___

3. Approximately how many times did you (the individual) go to each of the following in the past 12 months? (NOTE: DO NOT INCLUDE EVENTS THAT WERE SPECIFICALLY FOR PEOPLE WITH DISABILITIES.)

1 = More than 20 times
2 = 11-20 times
3 = 6-10 times
4 = 4-5 times
5 = 2-3 times
6 = Once
7 = Never in the past 12 months
9 = Unknown

Would you like to do this activity more often, less often, or is this the right amount?

1 = More Often
2 = Right Amount
3 = Less Often

	Frequency	Satis W/ Freq.
a. Go to the movies	___	___
b. Go to live theatre performance	___	___
c. Go to live popular music performances	___	___
d. Go to a sports event	___	___
e. YMCA/YWCA/YMHA or other athletic clubs/facilities	___	___
f. Community/civic groups	___	___

This question should be answered by the surveyor. You may have to ask a few questions and observe. The key here is, does this house fit into the community, and could it be purchased by any family?

4. In what kind of place does the individual currently live?

1 = Single family home (or mobile home) in a neighborhood
2 = Single family home (or mobile home) in a rural area
3 = Multi-family home or apartment in a community setting
4 = Rooming house or residential hotel
5 = Living facility specifically built or extensively renovated that would only be suitable for use as a congregate care facility
6 = Nursing home
7 = Institution

5. How many other individuals live at the same address as you (the individual)?

a. Family members/relatives ___ ___

b. Personal care attendants ___ ___

c. Other paid staff who live here always ___ ___

d. Other paid staff who live here sometimes ___ ___

e. Other individuals with disabilities ___ ___ ___

f. Other individuals without disabilities ___ ___

6. During the past few weeks have you (the individual) ever felt very lonely or remote from other people?

○
1 = Yes
0 = No
9 = Unsure

7. I'd like to ask you (the individual) about the people who live around here, but not at this address or facility. As neighbors would you say they are very good, fairly good, neither good nor bad, not very good or not good at all?

○
1. Very good
2. Fairly good
3. Neither good nor bad
4. Not very good
5. Not good at all
9. Don't know or no opinion

8. Of the ten families that live closest to you (the individual) here, how many would you say you know by name?
Enter exact number of families, 0 = none, through 10.

___ ___

9. Of these ten families that live close to you (the individual), how many have you ever visited with, either in their home or in yours?
Enter exact number of families, 0 = none, through 10.

___ ___

10. Do you (the individual) have any friends/acquaintances who you see regularly who do not have a disability?

○
1 = Yes
0 = No

11. Do most of your (the individual's) friends have a disability?

○
1 = Yes
0 = No

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence.

12. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, integration means, "the use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, and participation by persons with developmental disabilities in the same community activities in which nondisabled citizens participate, together with regular contact with nondisabled citizens, and the residence by persons with developmental disabilities in homes or in home-like settings which are in proximity to community resources, together with regular contact with nondisabled citizens in their communities." On a scale of 1 to 5, with 1 being totally integrated and 5 being totally segregated, how integrated do you (the individual) think you are?

1	2	3	4	5
Totally integrated				Not at all integrated

13. How important is it to you (the individual) to be integrated into the community?

○
1. Very important
2. Somewhat important
3. Neutral
4. Somewhat unimportant
5. Not important at all

F. PRODUCTIVITY

1. Which of the following categories best describes your (the individual's) current situation: Are you (the individual) (read list):

○

1. Working full-time for an employer, a workshop, or yourself
2. Working part-time for an employer, a workshop, or yourself
3. Unemployed but looking for work
4. Unemployed but not looking for work
5. Retired
6. Completely unable to work because of health problem(s)
7. Keeping house
8. Full-time student, employment trainee, or participant in vocational rehabilitation
9. Doing full or part-time volunteer work
0. None of the above

2. Have you (the individual) ever worked for pay? (If the answer is 0 or 9, skip to question 10.)

○

1 = Yes
0 = No
9 = Don't Know

3. How many hours in an average week do you (the individual) spend in working for pay?

___ ___

(Enter number of hours; if none enter 0 and skip to question 7)

4. What was your (the individual's) gross pay last week? (If unknown, enter 999.)

___ ___ ___ (enter in dollars)

5. What is your (the individual's) job title? (Job titles should be "forced" into one of the OES codes.)

____
Job Title

__ __ __ __ __ __ __ __ __

(Select an OES code from the chart)

6. How long have you (the individual) had this job? If less than 1 year, code 01.

___ ___ (Enter number of years.)

(If this is the individual's first job skip to question 10.)

7. How many hours per week (on the average) did you (the individual) work at your prior job? Enter 99 if unknown.

__ __ (Enter number of hours.)

8. What was your (the individual's) gross weekly pay (on the average) at your prior job? (Enter 999 if unknown.)

__ __ __ (enter in dollars)

9. What was the title of your (the individual's) prior job? Job titles should be "forced" into one of the OES codes.

____

Job Title

__ __ __ __ __ __ __ __ __

(Select an OES code from the chart)

10. How many hours last week did you (the individual) spend doing house work in your own home?

__ __ (Enter number of hours.)

11. How many hours last month did you (the individual) spend doing civic or community work or other volunteer work?

__ __ (Enter number of hours.)

12. How many hours last week did you (the individual) spend helping family, friends, or neighbors?

__ __ (Enter number of hours.)

For this question, the first sentence is there only to familiarize the surveyor with the language in the Act. You should only read the last sentence.

13. According to the Developmental Disabilities Assistance and Bill of Rights Act as amended in 1987, productivity means, "engagement in income-producing work by a person with developmental disabilities which is measured through improvements in income level, employment status, or job advancement, or, engagement by a person with developmental disabilities in work which contributes to a household or community." On a scale of 1 to 5, with 1 being very productive and 5 being not productive at all, how productive do you (the individual) think you are?

1	2	3	4	5
Very Productive				Not productive at all

14. How important is it to you (the individual) to be productive?

    1. Very important
    2. Somewhat important
    3. Neutral
    4. Somewhat unimportant
    5. Not important at all

G. Supports/Services/Assistance Needed

In this section we want individuals to think about the best possible array of services that they could possibly receive. This may have nothing to do with services the person is currently receiving. Please ask individuals to think about what services they would need most to foster independence, integration and productivity.

Which of the following supports, services or other assistance would provide the most help to you in living, working or going to school, and participating in the community? For supports and services that you are not currently receiving, please code the reason you are not receiving the support, service, assistance now, and what the level of need is for the assistance. For services you would need and are currently receiving, code 0 under reason for not receiving.

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = CRITICAL OR PRIMARY NEED
9 = DON'T KNOW

PRIMARY REASON FOR NOT RECEIVING THE SUPPORT, SERVICE OR ASSISTANCE

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO MY NEEDS OR DOESN'T LIKE THE SERVICE
6 = PERSON DIDN'T KNOW SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

SUPPORTS NEEDED

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

			Level of Need	Reason not Receiving
1.0	CASE COORDINATION SERVICES			
1.1	Case Management	1.1	___	___
2.0	RESIDENTIAL SUPPORTS			
2.1	Homemaking Assistance or Training	2.1	___	___
2.2	Housing Subsidy (e.g., Section 8)	2.2	___	___
2.3	Architectural Modifications	2.3	___	___
3.0	EDUCATIONAL SUPPORTS/SERVICES			
3.1	Early Intervention Services	3.1	___	___
3.2	Preschool Services	3.2	___	___
3.3	After School Tutor	3.3	___	___
3.4	Related Supports (e.g., aide, attendant)	3.4	___	___
3.5	Summer School/Programs	3.5	___	___
3.6	Adult Literacy/Basic Education	3.6	___	___
3.7	Vocational/Technical or Vocational Education	3.7	___	___
3.8	Post Secondary Education	3.8	___	___
4.0	EMPLOYMENT/VOCATIONAL/DAY SUPPORTS/SERVICES			
4.1	Employment Services (e.g., job coach)	4.1	___	___
4.2	Vocational Training Services	4.2	___	___
4.3	Psychosocial Rehabilitation	4.3	___	___
4.4	Adult/Child Day Care	4.4	___	___
4.5	Habilitation Services	4.5	___	___
4.6	On-site modifications at the work site	4.6	___	___
4.7	On-site aide/attendant	4.7	___	___

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

			Level of Need	Reason not Receiving
5.0	HEALTH SUPPORTS/SERVICES			
5.1	General Medical Services	5.1	___	___
5.2	Dental Services	5.2	___	___
5.3	Health Insurance (Private)	5.3	___	___
5.4	Payment for or Provision of Medical Equipment/Supplies	5.4	___	___
5.5	Payment for or Provision of Medication	5.5	___	___
6.0	INDIVIDUAL SUPPORT SERVICES			
6.1	Respite Care, In Home	6.1	___	___
6.2	Respite Care, Out of Home	6.2	___	___
6.3	Behavior Management Assistance/Training	6.3	___	___
6.4	Mental Health or Counseling Services	6.4	___	___
6.5	Protective or Legal Services	6.5	___	___
6.6	Physical Therapy or Related Services	6.6	___	___
6.7	Occupational Therapy or Services	6.7	___	___
6.8	Communication and Language Services	6.8	___	___
6.9	Attendant Care	6.9	___	___
6.10	Community Living Assistance or Training	6.10	___	___
6.11	Home Health Aides or Visiting Nurse	6.11	___	___
6.12	Adaptive Equipment/Assistive Devices and Training	6.12	___	___
6.13	Income Assistance (i.e., SSI)	6.13	___	___
6.14	Food Assistance/Food Stamps	6.14	___	___
6.15	Homemaker/Chore Services	6.15	___	___
6.16	Cooking/Meals on Wheels	6.16	___	___
6.17	Companion/Friend-Advocate Program	6.17	___	___
6.18	Self Help/Support Groups	6.18	___	___
6.19	Financial Management Assistance	6.19	___	___
6.20	Community Support Services	6.20	___	___

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

			Level of Need	Reason not Receiving
7.0	**TRANSPORTATION**			
7.1	Transp'n to and from work, school, day activity	7.1	____	____
7.2	Transp'n to and from non-daily activities (e.g., medical appointments, shopping)	7.2	____	____
7.3	Transp'n for leisure time (weekdays)	7.3	____	____
7.4	Transp'n for leisure time (weekends)	7.4	____	____
7.5	Vehicle Modification	7.5	____	____
7.6	Transportation Training (driver's education, use of public transportation, etc.)	7.6	____	____

For the items in the CAREGIVER SUPPORT SERVICES section, the caregiver should always be consulted. A caregiver is intended to mean someone other than the consumer. The questions are meant to be asked of a family member or other non-paid person.

			Level of Need	Reason not Receiving
8.0	**CAREGIVER SUPPORT SERVICES**			
8.1	Respite Care, In Home	8.1	____	____
8.2	Respite Care, Outside Home	8.2	____	____
8.3	Child Day Care	8.3	____	____
8.4	Homemaker/Chore Services	8.4	____	____
8.5	Behavior Management Assistance/Training	8.5	____	____
8.6	Family Counseling	8.6	____	____
8.7	Parent Training	8.7	____	____
8.8	Family Education	8.8	____	____
8.9	Genetic Screening and/or Counseling	8.9	____	____
8.10	Family Cash Assistance	8.10	____	____
8.11	Family Support Services (Other ______________)	8.11	____	____
8.12	Adult Day Care	8.12	____	____
8.13	Family Support Group	8.13	____	____

LEVEL OF NEED

1 = NOT NEEDED AT ALL
2 = SLIGHT NEED
3 = MODERATE NEED
4 = STRONG NEED
5 = URGENT OR PRIMARY NEED
9 = DON'T KNOW

REASON FOR NOT RECEIVING

1 = NOT ELIGIBLE BY TYPE OR DEGREE OF DISABILITY
2 = NOT ELIGIBLE BECAUSE OF INCOME OR MEANS
3 = SERVICE IS TOO EXPENSIVE TO OBTAIN
4 = SERVICE IS NOT AVAILABLE IN THE AREA
5 = SERVICE THAT IS AVAILABLE IS NOT APPROPRIATE TO NEEDS OR PERSON DOESN'T LIKE THE SERVICE
6 = PERSON DID NOT KNOW THE SERVICE EXISTED
7 = ON A WAITING LIST OR AVAILABILITY IS LIMITED
8 = ANY OTHER REASON
9 = UNKNOWN
0 = CURRENTLY RECEIVING SERVICE

			Level of Need	Reason not Receiving
9.0	OTHER SERVICES			
9.1	Recreation/Leisure Services	9.1	____	____
9.2	____________________(Specify)	9.2	____	____
9.3	____________________(Specify)	9.3	____	____

This instrument is adapted from:
The Final Survey Instrument
Submitted by:
Temple University
Developmental Disabilities Center/UAP
Research & Quality Assurance Group
Philadelphia, PA 19122

APPENDIX B:

LETTER TO SERVICE PROVIDERS

The
University of Mississippi

Research and Training Center for the Handicapped
304 Old Chemistry
University, MS 38677
(601) 232-5806

June 23, 1989

Dear

Under separate cover, Mr. Ed Bell has corresponded with you concerning a consumers survey that the University of Mississippi is performing under contract for the State Developmental Disabilities Planning Council of the Department of Mental Health.

The Developmental Disabilities Assistance Act of 1987 requires each state to contact persons with developmental disabilities in Mississippi to assess their needs. The results of this survey should enable us to make some recommendations regarding service availability and future funding. It is intended that the survey will also prove of much value to the Mississippi Developmental Disabilities Planning Council in planning services for Mississippians with disabilities.

In order to be able to accomplish this project, your cooperation and assistance is necessary and will be most appreciated. In the near future, we will call you to help set up appointments for us to meet with clients of your program, and to get your input as to how best we can do this project.

We sincerely appreciate your willingness to assist us in this endeavor. If you have any questions, please do not hesitate to contact us at (601) 232-5806. Thank you for your assistance.

Sincerely,

James Mann, Director

Please Note: In accordance with the Family Education Rights and Privacy Act of 1974 and subsequent amendments, the confidentiality of each respondent will be strictly observed. No identifying client information will be entered on the questionnaire, and no clients' name will be mentioned in the study.

August 14, 1989

Director
Mississippi Association for Retarded Citizens
3000 Old Canton Road, Suite 585
P.O. Box 5093
Jackson, MS 39216

Dear Director:

Under separate cover, Mr. Ed Bell has corresponded with you concerning a consumers survey that the University of Mississippi is performing under contract for the State Developmental Disabilities Planning Council of the Department of Mental Health.

The Developmental Disabilities Assistance Act of 1987 requires the state to contact persons with developmental disabilities in Mississippi to assess their needs. The results of this survey should enable us to make some recommendations regarding service availability and future funding. It is intended that the survey will also prove of much value to the Mississippi Developmental Disabilities Planning Council in planning services for Mississippians with disabilities.

We intend to conduct over 500 face-to-face interviews with both served and unserved persons to: assess needs; determine satisfaction with services; and ascertain whether services promote independence, productivity, and integration. We are currently in the process of identifying persons to be interviewed, and would appreciate your assistance with that effort.

In order to be able to accomplish this project, your cooperation and support is necessary, and will be most appreciated. In the near future, we will call you to help set up appointments for us to meet with a sample of developmentally disabled students, and to get your input as to how best we can do this project.

We sincerely appreciate your willingness to assist us in this endeavor. If you have any questions, please do not hesitate to contact us at (601) 232-5806. Thank you for your assistance.

Sincerely,

James Mann

Please Note: In accordance with the Family Education Rights and Privacy Act of 1974 and subsequent amendments, the confidentiality of each respondent will be strictly observed. No identifying student information will be entered on the questionnaire, and no client's name will be mentioned in the study.

P.S. Attached is fact sheet and questionnaire.

APPENDIX C:

LOCATION OF INTERVIEWS

LOCATIONS OF INTERVIEWS

1. Biloxi, Harrison County
    a. Biloxi Industries
2. Clarksdale, Coahoma County
    a. through Oxford Center for Independent Living
3. Greenville, Washington County
    a. through Oxford Center for Independent Living
4. Gulfport, Harrison County
    a. Cheshire Home
    b. de l'Epee Deaf Center
5. Hazlehurst, Copiah County
    a. Royal Maid Association for the Blind
6. Jackson, Hinds County
    a. Addie McBryde School for the Blind
    b. Jackson Center for Independent Living, Division of Vocational Rehabilitation
    c. Willowood Industries
7. Mendenhall, Simpson County
    a. Martinville Retirement Center
8. Oxford, Lafayette County
    a. Oxford Center for Independent Living, Division of Vocational Rehabilitation
    b. Lafayette Industries
9. Sanatorium, Simpson County
    a. Boswell Retardation Center
10. Starkville, Oktibbeha County
    a. Community Counselling Services
    b. Skills Unlimited
11. Tupelo, Lee County
    a. Royal Maid Association for the Blind
    b. Work Opportunities Resource Center

SUMMARY

17 Locations
14 Centers
11 Cities/Towns
9 Counties

APPENDIX D:
INDIVIDUAL CONSENT FORM

Survey of Consumers of Services
for Individuals with Developmental Disabilities
in Mississippi

INDIVIDUAL CONSENT FORM

The Research and Training Center for the Handicapped at the University of Mississippi, in conjunction with the Mississippi Developmental Disabilities Planning Council, is conducting a survey on how persons with developmental disabilities feel about the services they are receiving. The results of this survey should assist us in making recommendations for ways to improve these services. This study is being funded by the Department of Mental Health through Public Law 100-146, the Developmental Disabilities Assistance and Bill of Rights Act of 1987.

By signing below:

1. I agree to participate in this survey.
2. I understand that all the information I provide will remain confidential. My full name will not appear in any report or publication of the results. Rather, the results will draw conclusions based on groups of participants in the study.
3. I have read and understood this document.

Individual's Signature	Date

APPENDIX E:
CERTIFICATE OF APPRECIATION

THE UNIVERSITY OF MISSISSIPPI
AND THE
MISSISSIPPI DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

issue this certificate as an expression of appreciation to

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for participating in the

SURVEY OF CONSUMERS OF SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN MISSISSIPPI

and thereby helping the state to make needed improvements in these services.

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Dr. James Mann, Director
Research and Training Center for the Handicapped
University of Mississippi

____
Mr. Ed Bell, Director
Mississippi DD Planning Council
Department of Mental Health